Ethiopian Public Health Institute

National Data Management and Analytics Center for Health (NDMC)

Working Guideline (2nd version)

July 2021

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Abbreviations

AHRI	Armauer Hansen Research Institute
BoD	Burden of Diseases
CSA	Central Statistics Agency
DAMV	Data Analytics, Modeling and Visualization
DCP	Disease Control Priority
DHIS	District Health Information System
DRG	Data Repository and Governance
FMOH	Federal Ministry of Health
EPHI	Ethiopian Public Health Institute
EPHA	Ethiopia Public Health Association
EST	Evidence Synthesis and Translation GBD Global Burden of Disease
HSDP	Health Sector Development Program
HSTP	Health Sector Transformation Plan
ICT	Information, Communication and Technology
IHME	Institute for Health Metrics and Evaluation
INVEA	Immigration, Nationality and Vital Events Agency
M&E	Monitoring and Evaluation
MoH	Ministry of Health
NDMC	National Data Management Center
PPMED	Plan, Policy, Monitoring and Evaluation Directorate
SDG	Sustainable Development Goal
VERA	Vital Events Registration Agency

Summary

The Ethiopian Public Health Institute (EPHI) has given the responsibility by the Council of Ministers decree no 301/2013[1] to establish a national health data repository and to undertake research on national priority health challenges, public health emergency management and building national laboratory capacity. The institute is a technical wing for the Ministry of Health (MoH), having responsibility for generating strong evidence for high-level decisions including evidence that support epidemic alert, responses and mitigations, evidence for program inputs; evidence for developing, tracking and evaluating strategies, policies and for implementing information transformation agenda of the MoH including health information system (HIS) and digital health strategies.

In 2017, the institute has developed its first working guidelines to support the establishment of a National Data Management Center for health (NDMC). The center was established as EPHI's and MoH flagship initiative to deliver the institutes mandate given by the council of Ministers decree[2] and for the realization of the 2016 information transformation agenda of the MoH[3]. The impetus behind the establishment of the center was that despite the country's having multiple health and population data at national and sub-national levels, there was no recognized coordinating center to archive and process health data, and synthesize strong evidence to inform decisions at national and sub-national levels, priority health challenges and interests.

Upon its establishment, the center has taken advantage of the fast paced digital transformation and information technologies, which has propelled the center fast forward towards achieving its vision of being a center for excellence in health data management, evidence synthesis and translation in the country. Some of the notable achievements of the center are,

- Creating credible and reliable health data governance systems, procedures, guidelines to ensure data integrity, confidentiality and security as well as to facilitate data access and sharing
- Digitizing health data and information systems, creating standard repository, promoting digital health, make health data Findable, Accessible, Interoperable and Reusable (FAIR), improve quality, reproducibility and reliability of health data and researches.
- The center is serving as a national health data hub for archiving all health and health related data in the country and beyond with their respective meta-data, set data standards and regulations to foster data exchange and maximize data use.
- Building state of the art data systems and capacities for the realization of the center's vision not to be left behind in the highly progressive digital revolution; to support the national digital health and health information system strategies. Moreover, these capacities and expertise would pave the way for the center's vision of being a center for excellence; to support regional African countries, other sectors in Ethiopia, and the continent at large.

[1]FEDERAL NEGARIT GAZETTE. 2014. Regulation No. 301 120 13 Ethiopian Public Health Institute Establishment Council of Ministers Regulation. Page 7175

[2]FEDERAL NEGARIT GAZETTE. 2014. Regulation No. 301 120 13 Ethiopian Public Health Institute Establishment Council of Ministers Regulation. Page 7175

[3] Federal Ministry of Health. 2015. HSTP Health Sector Transformation Plan 2015/16 - 2019/20 (2008-2012 EFY)

- Transforming health data analytics using innovative scientific techniques, tools and methods including data science, machine learning/artificial intelligence such as neural network and deep learning, modeling and forecasting as well as the application of big data analytic techniques to wrangle, scrape, compute and manage large and complex health datasets.
- Advancing health data analytics by using a mix of epidemiological, climate,
- Mathematical and statistical modeling approaches as needed to integrate health data with econometric data, geospatial data, climate data, remote sensing and satellite data for disease intelligence, forecasting, predicting and for tracking progress and targets.
- Synthesizing and generating strong scientific evidence on disease intelligence, disease burden, economic evaluation, and coverage of interventions, tracking and evaluation of global, continental and national targets as SDG, GTP and HSTP using advanced analytics and evidence synthesis systems in collaboration with local, national, continental and international partners. This has momentous contribution to the health sector, the people, the country, the region, the continent and the global community at large.
- Foster digital evidence translation, data use platforms and scientific contributions to maximize utilization of data, information and evidence at various levels. Improving data and evidence availability and accessibility in the country and beyond using digital technologies, dashboards and visualization tools, and publications to reach out various users and actors including the public, decision makers, clients/patients, health care providers, health care managers, researchers, academic institutions, donors, implementing partners and other stakeholders.
- Collaboratively produced national and subnational burden of disease estimates for the country as part of Global Burden of Disease (GBD 2019) study. Sub-national burden of disease estimate for Ethiopia has been for the first time that help for evidence-informed decision at all levels.
- The center uses various collaboration platforms with local partners including regional health bureaus, regional public health institutes, health and demographic surveillance systems (HDSS), universities, governmental and non-governmental organizations, private consulting firms, continental and international partners. Such collaborations enable the center in building strong health data systems, data analytic capacities, shaping the practice of health data sharing and access, evidence generation and use in the country and beyond and to scale up the center's initiatives. The collaboration platforms are also used for joint grant seeking and advocacy purposes.
- The center has short-term in-service data science trainings, and fellowship programs to build data science, disease intelligence and disease modeling, and advanced health metric capacities across the country and beyond and to ensure scale up and sustainability of the initiative. The fellowship program for Postdoctoral fellow and public health fellow is designed to bridge gaps in technical expertise within the center by attracting high caliber experts from within and outside of the country as well as for ensuring sustainability and scale up of the center's initiatives to other places.
- For successful implementation of its activities and achieving its intended objectives, at present the center is structured into four interconnected units that have interdependent functions. These units are Data Repository and Governance; Data Analytics, Modeling and Visualization, Evidence Synthesis and Translations, and Burden of Diseases.

The guideline has used as a blue print to guide the center's functions and structures for four years. Over these years, the center has evolved into a highly dynamic and innovative center taking advantage of digital, scientific and technological advances, multidisciplinary team of experts and collaborations which shaped the value of data, data systems, health data analytics and evidence synthesis and translation. It is therefore necessary to revise its working guidelines to be abreast with current development and to document progresses made.

Chapter I: Introduction

Background

Ethiopia as most sub-Saharan African countries has large amounts of routine, program and research data collected by various health and social sectors using diverse data platforms. These data are mostly in silos, fragmented and poorly organized which presented a challenge for real time reporting and poorly inform local and national decisions, and health system responses. Moreover, the countries' health systems and research institutes have limitations in undertaking big and heterogeneous data analyses, which in turn undermines the values of available data to inform and influence high level strategic and policy decisions. These challenges call for transforming the conventional health data systems and data analytics to digital, advanced and innovative systems and techniques having the right expertise. Building big data analytic expertise and Data Science capacity in Africa is essential to exploit the great potential of innovative techniques including Data Science to solve highly complex and computationally demanding health issues from heterogeneous data. Data Science uses scientific methods, processes, algorithms and systems to extract knowledge and insights from many structured and unstructured health data employing supervised and unsupervised learning algorithms to ensure knowledge discovery from large health data collected from different sources[4].

For synthesizing high-level evidence high caliber technical experts are required and yet finding such expertise at national levels has been a challenge. There have been long standing challenges to track progress and evaluate implementation of global goals as SDG, national plans as GTP and health sector plan as HSTP I and II. Formulating evidence-based policies, strategies and program in Ethiopia have double burden constraints. Having limited and fragmented health data on the one hand which has limited data analytic and evidence synthesizing capacity on the other hand sustained the production of weak evidence. The poor accessibility of available evidence is also adding to the problems[5]. Consequently, health policies, strategies and program supposedly derived from a comprehensive view of health and health related evidences across time, geography and population in Ethiopia are in short of the needed high-level evidence.

Now a days' improving health data and access to it is becoming fundamental for better health, whereby developing countries are required to make health data a public good. Following the World Health Organization (WHO) recommendations to establish and strengthen health information systems, digital health and vital statistics for evidence driven decision[6], the Ethiopia's first Health Sector Transformation Plan (HSTP I) for the year 2015-2020 has made Information Revolution (IR) as a core agenda. The major goal of the Information Revolution is "to maximize the availability, accessibility,

[4] Uthayasankar Sivarajah, Muhammad Mustafa Kamal, Zahir Irani, Vishanth Weerakkody. Critical analysis of Big Data challenges and analytical methods. Journal of Business Research, Volume 70, 2017, https://doi.org/10.1016/j.jbusres.2016.08.001

[5] Hibret Tilahun, Jessica Flannery& Peter Berman. Review of Local and Global Practices Global Practices on Evidence-Informed Health Policy: Recommendations for Ethiopia. Feb 2016

[6] Federal Ministry of Health. 2015. HSTP Health Sector Transformation Plan 2015/16 - 2019/20 (2008-2012 EFY)

quality, and use of health information for decision making processes through the appropriate use of Information and Communication Technologies (ICT) to positively impact access, quality, and equity of healthcare delivery at all levels". For its implementation Information Transformation Roadmap (IRR) was developed, which calls for a fundamental shift on the way health data is collected and utilized and the application of IT to advance public health and biomedical data analysis and evidence generation (11, 12). Being a research wing for the MoH, EPHI has taken the responsibility to implement the major activities set out in the Information Revolution agenda. Moreover, the EPHI's strategic framework sets forth the goal of providing assistance on the use of research for decision-making, and priority setting.

Health and population data sources in Ethiopia and their institutional mandates

Ethiopia strives to improve population statistics and public health metrics through availing valid, reliable and representative data by establishing responsible agencies and institutes with a clearly defined mandates.

Central Statistical Agency (CSA) is the main agency for collecting, compiling and disseminating official statistics, including vital statistics from population and housing censuses and household surveys. CSA is given a mandate by the law to coordinate the country's statistical activities to ensure the use of uniform statistical concepts, definitions and classifications nation-wide. CSA has given a mandate to conduct census, nationwide, region wide and regular surveys and 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[7]. Nevertheless, according to the Civil Registration law of 2012, the information gathered by the vital events registration agencies on births, marriages, divorces and deaths are compiled for statistical purposes and disseminated by CSA[8].

Vital Events Registration Agency (VERA) was established in 2013[9] to implement civil registration and vital statistics (CRVS) system in Ethiopia. VERA was established as the federal public administration autonomous organ to direct, coordinate and support the registration of vital events at national level, and to centrally organize and keep records of vital events[10]. These are birth, marriage, divorce and death. VERA activities are interfaced with other sectors and operations[11]. VERA and MoH have an agreement to complement each other's work through a time bound signed memorandum of understanding. MoH provides notifications of occurrence of births and deaths in health facilities including cause of death information. MoH prepares the notification forms in consultation with VERA. CSA has given the responsibility by the 2012 civil registration law to compile, the information gathered by the VERA on births, marriages, divorces and deaths for statistical purposes and to disseminate the information.

[7] A proclamation to establish Central Statistical Agency No.442/2005
[8] Proclamation No.760/2012.Registration of Vital Events and National Identity Card Proclamation
[9] Proclamation No.760/2012.Registration of Vital Events and National Identity Card Proclamation. …….Page 6497
[10] Establishing vital events registration and strengthening Draft for consultation at the CRVS technical consultation meeting, Addis Ababa, 28-29 April 2014
[11] Proclamation No.760/2012.Registration of Vital Events and National Identity Card Proclamation

Currently, VERA has changed its name to Immigration, Nationality and Vital Events Agency (INVEA).

Ministry of Health (MoH) is the main entity responsible for improving population health at large. It has several agencies delegated for different tasks including health data generation, analytics and synthesis. The MoH's Plan, Policy, Monitoring and Evaluation (PPMED) directorate is largely responsible for routine and administrative data collected from health facilities, from the community and notifying to VERA the births and deaths events that occurred at health facilities. MoH uses several Health Information Systems including the current board based District Health Information System (DHIS2) platform, which collects and archives health data collected from all health facilities.

Armauer Hansen Research Institute (AHRI), is a technical arm for FMoH. Its mandate is to undertake biomedical, clinical and medical biotechnology research including clinical trials, adapt and implement scientific technologies to improve clinical care, and build capacity of higher education[12].

Ethiopian Public Health Institute (EPHI) is the technical arm for the MoH. It's responsibilities are to implement the health information strategies including digital health and information revolution agenda of the MoH; 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 to provide assistance to regions and other entities conducting research[13]. Moreover, as an independent legal entity, EPHI has given the responsibility to establish a national health data repository by the Council of Ministers decree number 301/2013[14].

Others: including various national and sub-national institutes and agencies including regional health bureaus, regional public health institutes, health and demographic surveillance sites, universities, research centers, professional associations, non-governmental organizations are undertaking different researches, routine services, survey, surveillance and collect cross-sectional, longitudinal, clinical, biomedical, routine health and health related data and other forms of data.

All the aforementioned institutes and entities collect data often using different platforms; most of the data are in silos, and are managed and governed differently at different levels. These present serious challenge to have common data platforms to make the health data systems interoperable, interconnected, and to facilitate pooled analysis. All these negatively impact the generation of the highly needed strong evidence to inform policy decision as health policy is supposedly derived from a comprehensive synthesis of health and health related evidences in Ethiopia[15].

[12] Council of Ministers Regulation to provide for the establishment of Armauer Hansen Research Institute No.376/2016

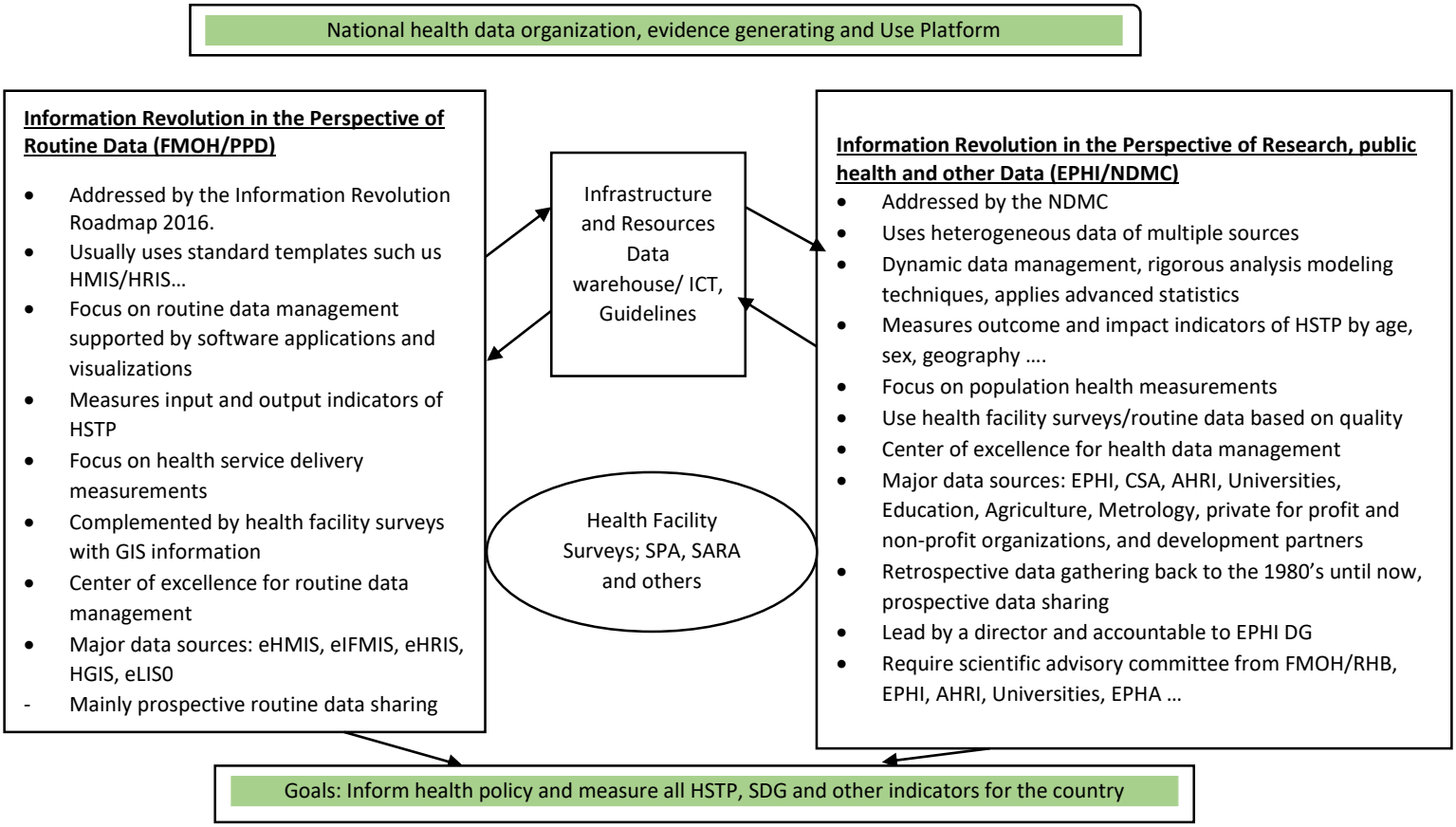
[12]FEDERAL NEGARIT GAZETTE. 2014. Regulation No. 301 120 13 Ethiopian Public Health Institute Establishment Council of Ministers Regulation. Page 7175

[13]Hibret Tilahun, Jessica Flannery& Peter Berman. Review of Local and Global Practices on Evidence-Informed Health Policy: Recommendations for Ethiopia. Feb. 2016

Organizational and functional relations of the different health data systems, data sources and major actors in Ethiopia

As described above, in Ethiopia, different organizations collect health and health related data with various platforms. Establishing functional coordination mechanism is very important for the data to be properly archived, accessed, shared and utilized by a wide range of users from policy makers to individuals for improving health and wellbeing. Data integration and data triangulation enhance the quality, value and usefulness of analytic outputs and for generation of valid evidence. Evidence generated in such a way has the power to influence high-level decisions. The research data collected at EPHI, Armauer Hansen Research Institute (AHRI) and other research institutions including universities, CSA and VERA complement the routine health data collected from health facilities through the DHIS2 and other platforms to generate powerful and valid evidence. To ensure complementarity and synergy of the different data sources, the country would require having an overarching health data governance systems and procedures,

As indicated in figure 1 below, evidence generated from the routine data & from the research data complement each other's limitations and hence can be used for tracking progress of various health interventions, policies and strategies effectively & sustainably. These evidence sources are equally important to inform decisions. Moreover, the two systems can share their infrastructure, ICT resources, guidelines and manuals to have greater impact in the country's' digital health transformation[16]. To this end, it is important to have a framework that coordinate data sources, data user, evidence generators & evidence users.



[16]National Data Management Center (NDMC) for health, Ethiopian Public Health Institute, Working Guidelines, Revised Version, Addis Ababa, Ethiopia, June, 2017

Figure 1: A coordination framework for health and health related data in Ethiopia including data from routine health systems and research.

Chapter II: Health Data Management at EPHI past and present

EPHI is the oldest and the strongest public health institutes in Africa. Its core functions are Research on priority public health, nutrition, clinical and biomedical science; Managing Public Health Emergencies; National Laboratory Capacity building; and setting national health data repository, data systems and transforming health data analytics to generate strong evidence that can inform high-level decision and disease intelligence. Being a federal institute, EPHI has a responsibility to support all the sub-national health bureaus and the health sector at large. However, the role of the institute in creating data systems, strong analytics and evidence synthesis and translation were poor before the establishment of NDMC.

Past EPHI health data system

EPHI used to have a conventional system like many research institution, predominantly focusing on research for academic merits and advancing science with limited focus on supporting health strategies, programs, policies and intervention although the later were the core deliverables of the institute. This tradition was against the institute's 2015/16 strategic framework and the HSTP I. The EPHI's strategic framework sets forth the goal of providing assistance on the use of research for decision-making, and priority setting. Achievement of HSTP's goal of greater equity and quality, through the use of evidence would require a fundamental shifts in how health policy issues are identified, considered, acted upon, and monitored – a shift that is based upon broad trust in - and support for - the data that are available. These would require a shift on the way health data and information are collected, analyzed and health evidence are synthesized and disseminated.

Matching with its convention system, EPHI research and other data generating individuals were solely handing their own data systems/or relying on ICT support due to lack of recognized central data repository, governance and data security systems at the institute. In 2016, although, the institute has developed a Data sharing and management guideline, individual researcher was left to carry the burden of data access and sharing requests on their own. These had caused irregularities, delays, frustration with partners and spoiled the image of the institute.

Despite this clear data-driven vision of EPHI and MoH, strong support at different levels and the responsibility given by the council of ministers to EPHI, there were serious challenges to establish a national health data management center at EPHI. Through, thorough and continues dialogue and deliberations with high level decision makers at EPHI, MoH and concerned stakeholders, the institute has developed its first working guideline to support the establishment of a National Health Data Management center for health (NDMC) in July, 2017 under the leadership of the MoH[17]. NDMC is a flagship initiative by both by the MoH and EPHI.

[17] National Data Management Center (NDMC) for health, Ethiopian Public Health Institute, Working Guidelines, Revised Version, Addis Ababa, Ethiopia, June, 2017

Major drivers of NDMC's establishment include

- Large amount of health and health related data are produced in the country including EPHI but due to lack of a national coordinating body most health data are in silos, fragmented, poorly organized
- There was a need to create national repository/databases for health and health related data, automating the data systems
- Despite availability of data sharing and guidelines data sharing and access were not standardized and were disorganized
- There were gaps in data governance systems, structure, reliable and secure data storage
- there were gross limitations on technical and technological capacity to transform the existing health data systems to generate strong evidence for high level policy decision
- The need to build digital data analytics and visualization platforms to maximize data and evidence use
- The need to have health data experts, support national health data analytic expertise
- Limited technical expertise to apply robust data analytics and evidence synthesis to generate strong evidence
- The need to have sub-national burden of disease estimates for Ethiopia and health metrics capacity and
- Overall the need to have strong-evidence for decision at different levels to improve population health

Present EPHI health data systems

EPHI has established the NDMC with the ultimate goals of improving the health status of the population through collating reliable, valid and comprehensive data; undertaking advanced data analytics; synthesizing and disseminating high quality evidence; measuring and tracking health program performance at different levels and supporting evidence translation to policy in the country. The center is dedicated to implement the FAIR (findable, accessible, interoperable and reusable) principles for public health data, to build data systems and capacity in the country and beyond and to apply data science for solving priority public health research challenges among other responsibilities. Although, it has taken sometime for EPHI to establish NDMC, following its establishment the center has made significant progress in creating advanced data systems, ensuring data/information access, exchange, in advancing data analytics and in synthesizing and availing strong evidence to inform decision at MoH and other relevant parties.

The first NDMC Working Guideline, which was developed in 2017 supported the establishment of the center and used as a blue print to guide the center's functions and structures until July 2021. Since its establishment, the center has evolved into a highly dynamic and innovative center taking advantage of digital, scientific and technological advances and multidisciplinary team of experts that shape the value of data, data systems and health data analytics. The center has followed a form of 'agile methodology' to manage the center's activity by breaking it up into several phases. It involves constant collaboration within the center's several units and likeminded collaborators with continuous improvement every

time. This enabled the center to accommodate evolving needs, changing priorities, and emerging health challenges. The center seizes opportunities, emerging innovations, and scientific advances in technology and techniques and above all on the power of data.

Chapter III: The National Data Management Center for health (NDMC)

The NDMC intends to bridge the gaps in data systems and transforming data analytics and evidence synthesis and translation capitalizing on existing and emerging strategies, opportunities including information revolution policies and strategies of the country, locally available research infrastructures, technologies, high demand for quality data for health decision, available local and international collaborations, and available multiple health and health related data sources to achieve its vision. NDMC process and manage already available data using rigorous scientific methods, to create research collaboration platform with local and international agencies, to draw national research agenda and develop data sharing culture, and to use resources efficiently and build evidence synthesis and dissemination capacity in the country.

Moreover, the NDMC provides easy access to quality data. This can significantly improve efficiency in obtaining and analyzing national and international population health data, can save cost and investment to generate primary data, and use of research findings for evidence informed decisions, innovation and advancing science and improve research integrity. The center implements the FAIR data principle to pave the way towards open health data systems and open data access. Moreover, this approach would enable to create data be findable and accessible for computational systems and to further make data systems to interoperate and reuse data with none or minimal human intervention. The NDMC establish systems that prevent data loss, reduce the cost of data storage, reduce financial burden on researcher for data collection and archiving, to ensure security, access and availability with the aim to support scientific works, research institutes and researchers. The NDMC interconnect and integrate data/information systems to foster data exchange and information sharing at local and international levels through high level secure channels. The national health policy promotes health information resources to be widely available and accessible to all, whereby the NDMC has taken this responsibility. The NDMC bridges the people who produce/collect data with the people who use data to generate information and with the people who generate evidence from the data and with the people who use evidence including decision makers.

NDMC builds strong partnership through a comprehensive and transparent national data sharing policy with several data sources outside of EPHI including but not limited to MoH, CSA, VERA, National Plan Commission, local universities, sub-national health bureaus, national public health institutes, DHSS, local and international NGOs (Figure 2 and 3).

Vision

To be a center of excellence in health data hub, open data systems, advanced analytics and disease intelligence, synthesizing and translating health evidences in Africa.

Mission

To improve health and wellbeing of the population through enhanced health data repository and governance systems, innovative digital health data systems, advanced analytics and visualization, generating high quality scientific evidence, and informing high level decisions at different levels. The mission encompasses;

- Establishing data systems and digital platforms for continuous collection and archival of health and health related data/information in the country to serve as a national standard, safe and secured health data repository to be an African regional health data hub, and to foster open data sharing to live up to the FAIR data principles.
- Establishing digital platform and data governance structure and systems to ensure open access to health data, availing health and health related data/information for the public on demand according to the nature of the data/information.
- Transforming health data analytics and result representations using cutting-edge techniques, methods and applications that blend mathematical and rigorous statistical theories and techniques to advance health data analytics, modelling, predicting, projecting, forecasting, integrated analysis, and heterogeneous analysis and through building interactive data analytic digital platforms for local, sub-national, national, continental and international consumptions
- Applying advanced health data analysis and basic concepts of data science such as artificial intelligence, machine learning, data mining to discover useful patterns and natural clusters in health data, to build robust models that are capable of predicting future events for formulating proper decisions and policies to be taken accordingly
- Synthesizing evidence to measure, monitor and track progress in policy implementations; national, and global strategic targets as in Sustainable Development Goal (SDG), HSTP II, progress in disease prevention and control as well as in program implementations with the applications of robust scientific methods to provide timely, strong and quality evidence having local, national, continental and global significance.
- Maximizing data and evidence use by decision makers, public to inform health policies, strategies, programs, innovations and for the public to inform personal health promotion and disease prevention and for academic purposes

Goal

The goal of NDMC is to create standard health data repository, create open data system and open data access by ensuring strong data governance and facilitating data sharing and access; implement standard data management and robust advanced health data analytics; synthesis evidence to improve public health practice and policy.

Key strategies

NDMC has five key strategies;

Strategy 1: Build national and regional capacities including human capital, digital infrastructure, systems and networks to ensure safe and secured data storage, sharing, access; systems and expertise for health data analytics (mathematical, epidemiological, geospatial and climate modeling, forecasting, data science, data mining, machine learning, integrated, heterogeneous and big data analyses); as well as systems and expertise to ensure advanced evidence synthesis and translations (**Capacity**)

Strategy 2: Establish national standard repository and databases for health and health related data within NDMC, archive data, publish meta-data, facilitate data access and sharing. Advancing public health through the development and application of data science, advanced statistical, climate, epidemiological, geospatial and mathematical modeling, computational methods, and visualization techniques to improve data and evidence availability and accessibility for local and international users **(Data)**

Strategy 4: Ensure local and international funding to undertake the different health and health related researches **(Funding)**

Strategy 5: Ensure utilization of data, analysis outputs, estimates and population health evidence for decision at MoH and key partners **(Utilization)**

Strategy 3: Establish and strengthen local and international collaboration for the realization of the aforementioned four strategies of the center **(Collaboration**)

NDMC on EPHI's strategic plan

At present, the institute is preparing its third costed 10 years strategic plan aligned with the country's 10-year development plan and with the second HSTP II of the MoH. One of the core activities of the EPHI's strategic plan is enhancing national health data repository, analytics through the application of data science and health metrics sciences, burden of disease estimates, digital health and information systems, where NDMC is responsible for its implementation. In this strategic objective, four strategic directions with major and detail activities, expected results, indicators and targets are described. The strategic directions are 1) Enhancing national health data repository, data security systems and strong data governance systems and maintain database interoperability; 2) Advancing public health through the development and application of data science, advanced statistical and mathematical modeling, computational methods, and visualization techniques; 3) Enhancing national, sub-national and local burden of diseases estimate using health metrics measurements; and 4) Advancing evidence synthesis, policy analysis, and translation for informed decision making.

Chapter IV: 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 2).

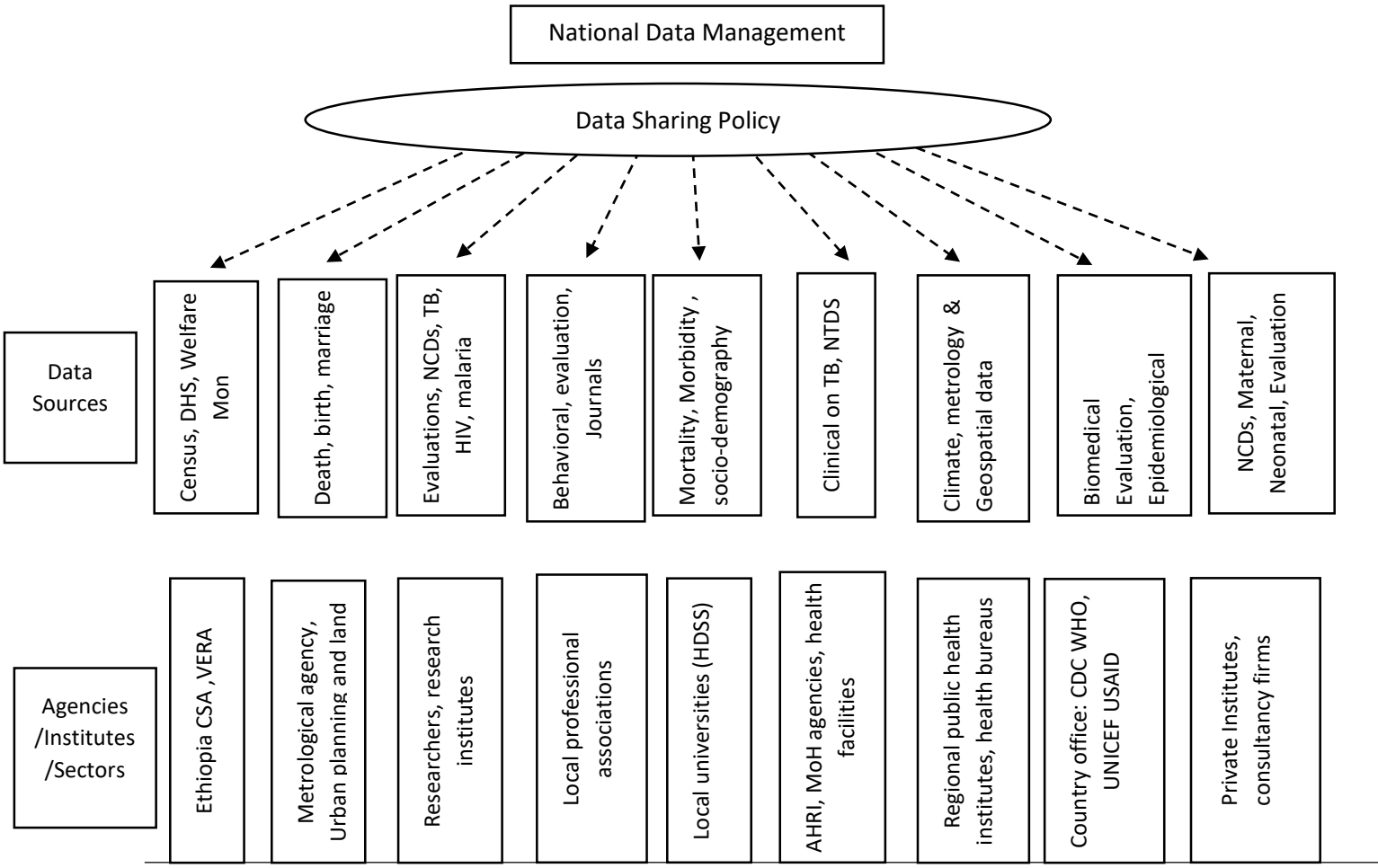


Figure 2: Functional relationship of NDMC with local research institutes and international agencies to access all data inputs and provide outcomes to potential users of the center

The core processes are data collection from different sources within and outside EPHI, store the data with different databases, process the data with standardized techniques, apply rigorous scientific methods and techniques, provide estimates and avail health data for public use based on request. To provide relevant evidence, it is critically important to pool primary and non-primary data to the center using data access and sharing modalities.

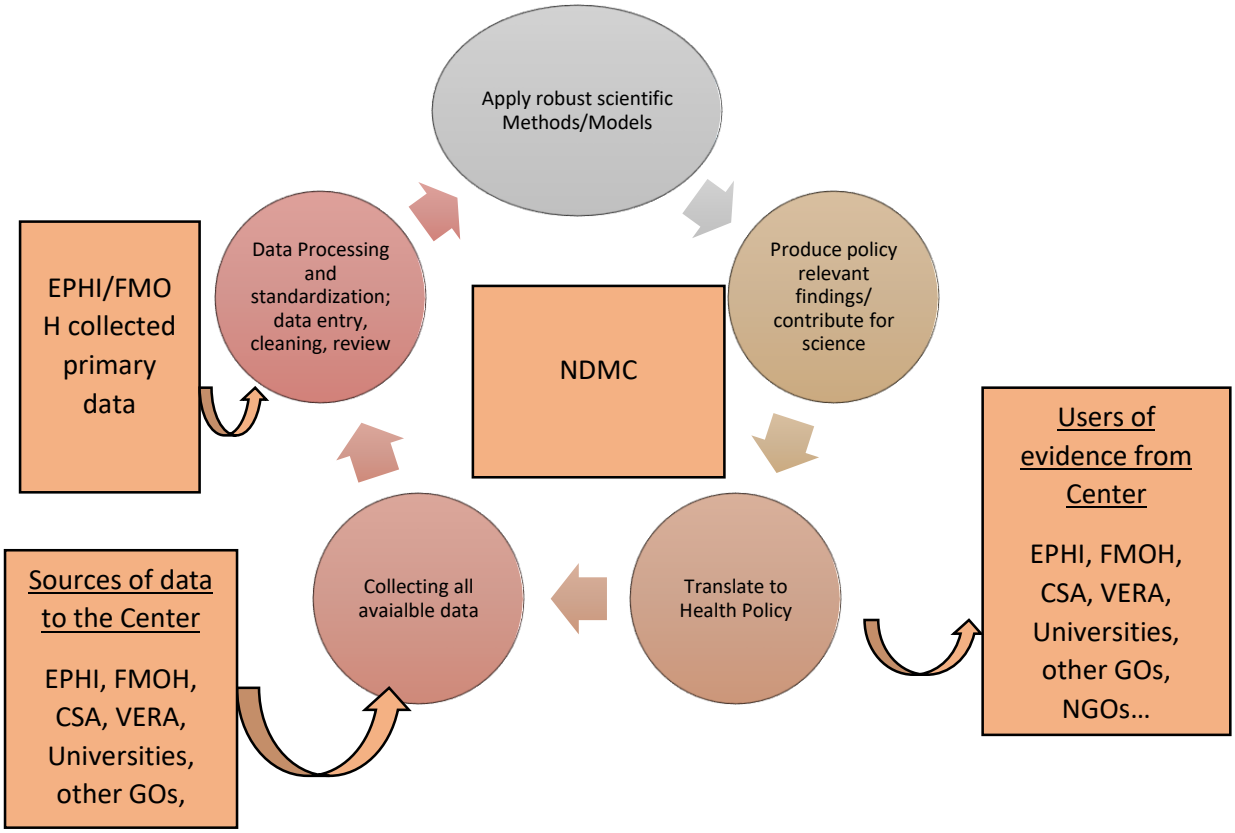


Figure 3: The NDMC data management and processing cycle

Accessing available data in the country

Data sharing remains a major challenge for NDMC as the culture and practices of sharing health data are underdeveloped in Ethiopia, as in many other settings. EPHI and MoH are developing National Data Access and Sharing directive/guideline, for guiding research institutes, health care actors, agencies and researchers to share their research data as open as possible to NDMC, taking privacy constraints into account. The directive/guideline that EPHI and MoH are developing will reinforce and empower institutions and universities to develop their own institutional data sharing guides. The directive/guideline streamline with IRB, technology transfer, and information technology policies and procedures. The directive/guideline encourages integration of data sharing plans as part of funding policies and guide appropriate data sharing requirements by fund providers, and recommend that they consider a proposal's data sharing plan as a scientific contribution. The directive/ guideline give direction to consider recognition procedures for data contributor. It also articulates the need for educating investigators, researchers, health care worker and other relevant actors on responsible data sharing and reuse practices through class work, mentorship, and professional development including the FAIR data principles. The directive/guideline promotes a framework for deciding appropriate data sharing mechanisms, platform and encouraging data sharing practices as part of publication policies. The directive/guideline addresses the need for funding the costs of data sharing, support for repositories, the adoption of data sharing infrastructure and systems/platforms. Moreover, it encourages research on best data sharing practices and to publish experiences to foster exchange of best practices. In addition, EPHI and MOH develop plan for the implementation of the directive/guideline and advocate using workshops and various mediums for responsible data sharing.

Chapter VI: NDMC Organogram, function and structure

NDMC organogram

The NDMC is accountable to the General Director of EPHI. The center has functional relationship with data generating directorates and other directorates of the institute. The NDMC intends to leverage on public health and biomedical data collected within EPHI by the different EPHI directorates' including; Public Health Emergency Management (PHEM), National Laboratory Capacity, Research and Technology Transfer (RTT), Monitoring and Evaluation, Scientific and Ethical Review Office, National Training Center and others. As shown in Figure 3 NDMC has functional relation and serve the different directorates of EPHI pertaining to administrative, managerial and governance decision on data systems, data analytics resources and data access and sharing. Creating collaborations, capacity building, grant seeking, data infrastructure development and project management activities are integrated within each unit of the center. *(Visit EPHI website: ephi.gov.et)*

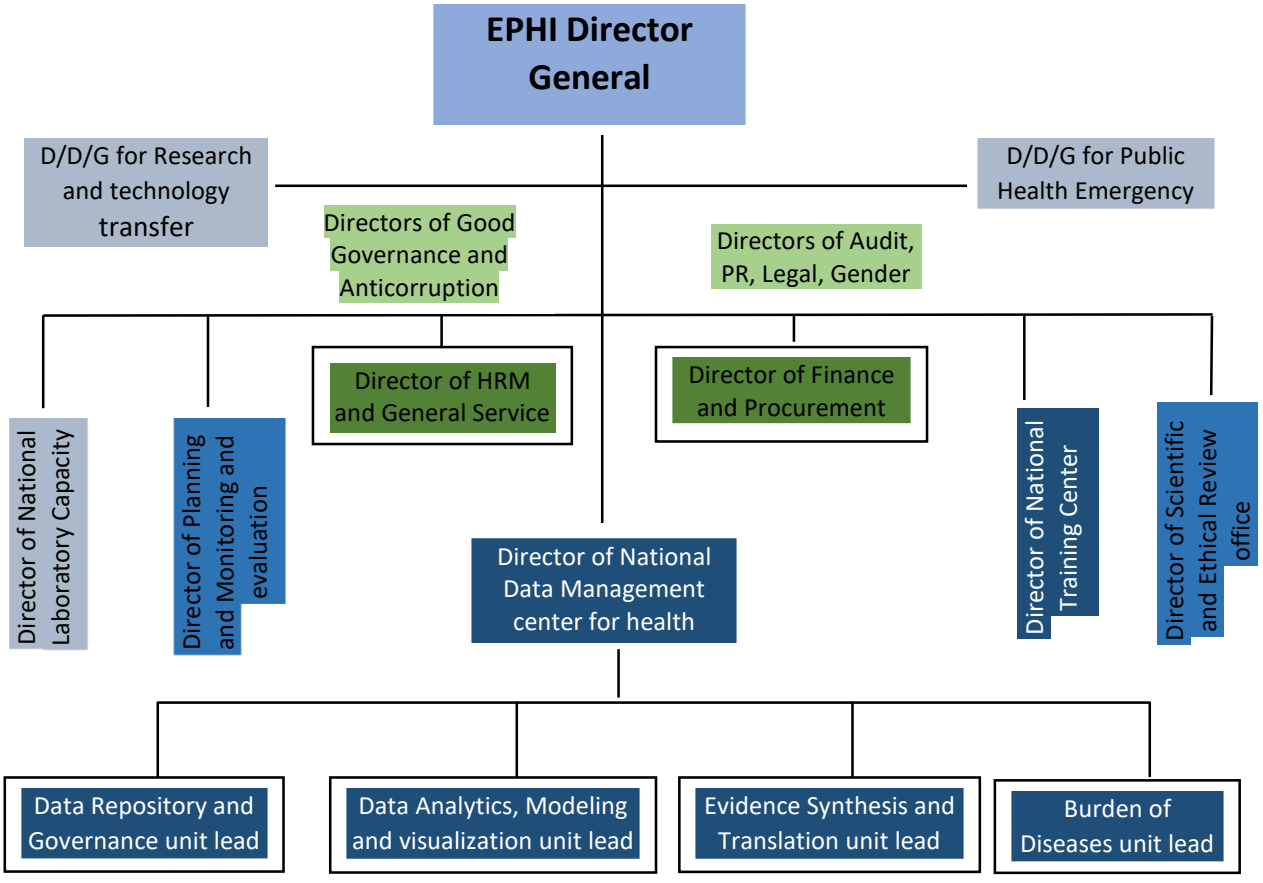


Figure 2: Organogram of EPHI and the National Data Management Center for health

NDMC functions

- Creating a coordinated and standard digital health data repository that support continuous collection, archiving, storage of health and health related data in the country obtained from

various sources including research institutes, NGOs, CSA, VERA, academia, universities, health and demographic surveillance sites, regional, zonal and woreda health bureaus, meteorology agency (climate and weather data); data from road traffic accident registration, professional association, cancer society as well as from international health data repositories where data can be legitimately accessed.

- Establish strong health data governance. The center is responsible for establishing reliable, safe and secured data access and sharing platforms, procedures; create interoperable data systems and to implement the FAIR (Findable, Accessible, Interoperable and Reusable) data principles on health data.
- Advancing health data analytics using cutting edge statistical, epidemiological and mathematical computations, metrics science, analytics sciences and techniques including heterogeneous data, big data and integrated data analytics, artificial intelligence, machine learning and data mining, modeling, forecasting, projection, tracking, prediction and evaluation to generate strong evidence and to build visualization platforms including dashboard to ensure analytic outputs are reaching to wide range of users.
- Synthesizing strong evidence to inform health and health related policies, strategies and programs including progress tracking and evaluation of HSTP, Growth and Transformation Plan (GTP), SDG, other global, continental, national and sub-national targets using a range of perspectives as economic/economic evaluation, disease control priorities, disease burden estimates, policy analysis. Moreover, the center conducts 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. The center proactively seeks and respond to evidence queries from policy or program decision makers at MoH; provide support to academic institutions and jointly train graduate fellows focusing on data science, evidence synthesis and dissemination.
- Maximizing health data and evidence utilization through open data systems and evidence translation platforms respectively to reach out decision makers, stakeholders, media and the population at large. These include producing evidence briefs, visualization, dashboard, social media and using conventional evidence translation platforms.
- Capacity building is one of the major functions of the center which uses different approaches. This capacity building endeavor to foster in house capacities and for key partners and collaborators to achieve the objectives of the centers, ensure scaling up and sustainability. 1) Developing and implementing accredited short-term trainings on FAIR data principles, data science, heterogeneous data management, advanced statistical and mathematical techniques and applications, geospatial data analysis, systematic review and evidence synthesis, evidence to policy translation. The EPHI's training center play significant role in coordinating the trainings. 2) fellowship programs for postdoctoral and public health fellows to attract high caliber experts 3) Data science fellowship, internship and mentorship trainings opportunities are part of the capacity building initiatives for local, national, regional and continental partners including the health sector and universities. 4) Identifying local and international training opportunities for staff who directly or indirectly serve the center is another capacity building endeavor. 5) Technical workshops and seminars on various areas including research methods, techniques on

epidemiological and burden of disease analytics, disease control priority, evaluation and biomedical data management, evidence synthesis and systematic reviews are also incorporated in the capacity building and networking strategies of the center. Hiring high caliber multidisciplinary experts using financial support from projects.

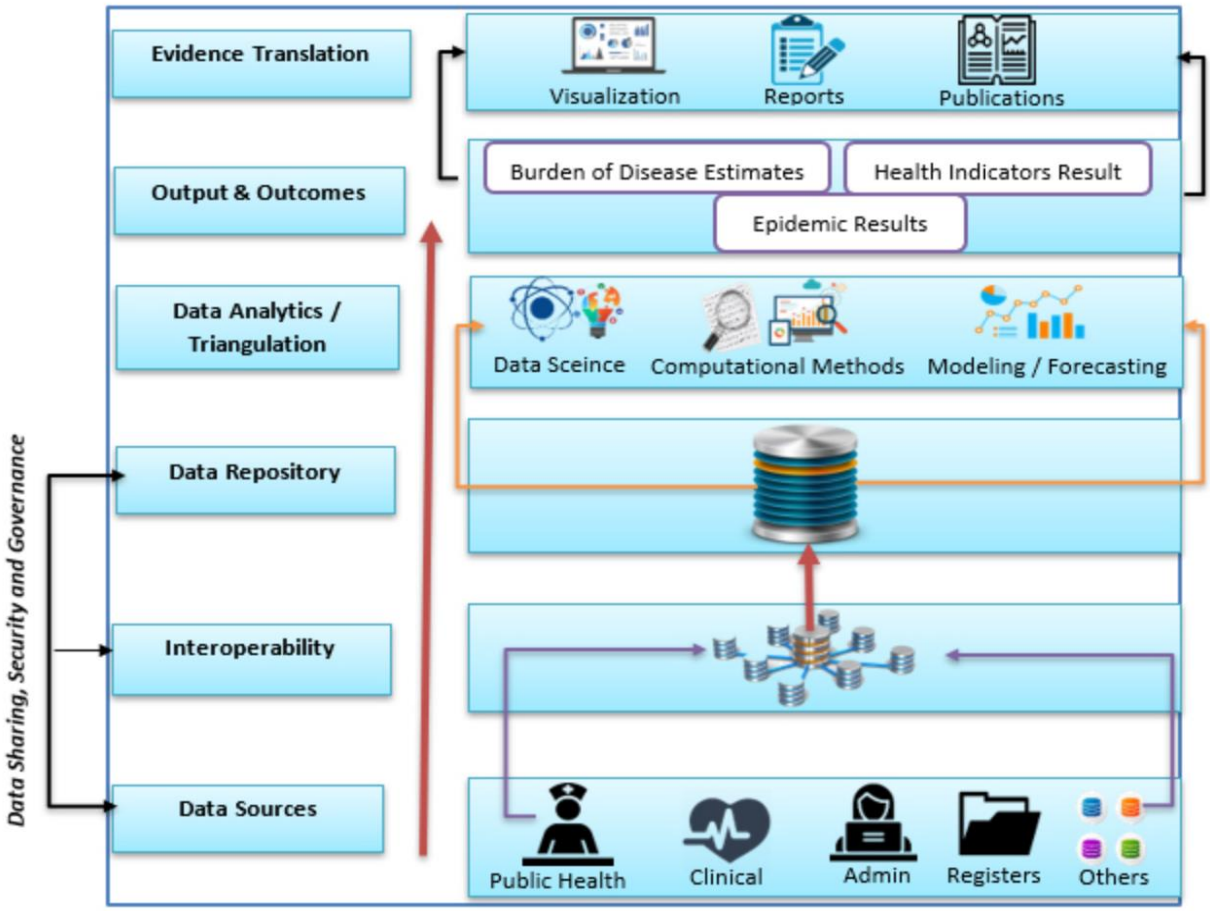


Fig 5: Flow diagram of NDMC activities

NDMC structure

Currently, the NDMC has four units. All the units of the center have interdependent functions and interconnected structure to achieve the broader objectives of the center.

Data Repository and Governance (DRG) unit

The role of this unit is to map health and health related data sources with their respective data types. To map data sources, various approaches have been used including web search, technical reports, published articles, research protocols submitted to EPHI Institutional Review board (IRB), conference preceding, personal communication, academic and dissemination forums. The data mapping includes retrospective and prospective data types. After mapping, the unit sorts out the format and contents of identified data, then approaches the primary owner/generator of the data using the official procedure (Fig 6).

This unit builds national health data repository, for archiving retrospective and prospective data collected from different sources. The health data repository has a highly secured digital platform with daily back up to protect the system from potential physical and cyber security threats. Data repository has been building with two-factor authentication including data mart, which has high storage for health and health related data and implementing a data warehouse with a data quality monitoring system.

Creating digital health data Repository, Tracking and Database System (RTDS) to enhance open data system for the visibility of data sets to the public and to encourage data use is another activity of the unit. The team develops meta-data for each dataset archived within the repository. The datasets are catalogued and indexed using standard systems such as key words and search engine recognized system to support easy access and data exchange (Fig 6). Using machine learning (neural network) the team has developed automated key word systems. To standardize the unit's day to day data archiving and cataloguing activities and routines, the team develop standard operating procedures and procedure manuals.

The unit is responsible for improving the quality and integrity of health data. Using data quality assessment checklists, the unit reviews dataset to ensure its quality and to automate data quality assurance methods/ procedures. The data quality assessment findings serve as a feedback for data generating entities to improve the quality of their data. The team undertakes data standardization and classification activities to standardize the data and to maximize utilization. Introducing a system for grading data quality and making recommendation is another data quality assuring activity of the unit.

The unit establishes strong health data governance structures and systems including guidelines for data access and sharing, data governance counsel, digital platforms for data sharing and access, support drafting national data sharing regulation and proclamation (Fig 6). Data and information security are core element of the center's activity, whereby this unit has the responsibility to ensure data security and privacy through data encryption, establishing strong passwords, regular backup, putting up strong firewall and updating programs regularly is also the responsibility of this unit. Moreover, all the center staff signed data confidentiality and privacy agreement upon joining the center. Strong data governance enhance the center's move towards having an open data system and open data access to advance open research landscape, improved research integrity, innovation, and discovery (FAIR Principle). The unit aspires to have a national data-quality governing body to function through established standard process engaging various health data actors.

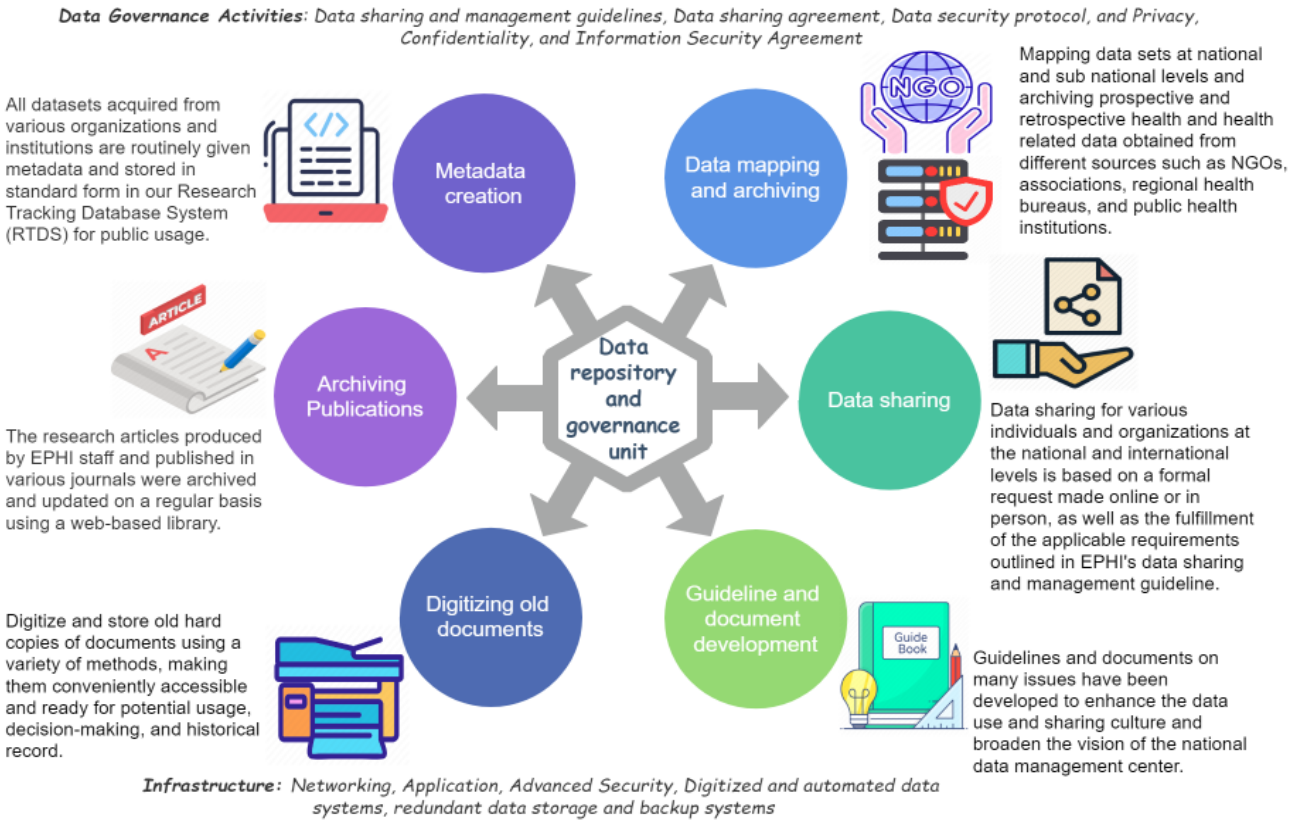


Figure 6: Major activities of the data repository and governance unit

The unit has established digital systems for data access and sharing to and from the center developed using the 2019 revised EPHI data management and sharing as a foundation (Fig 6). The unit follows the fundamental principles of national and institutional data sharing guidelines, which promotes maximizing data use. The data access and sharing routines of the unit is governed by national guideline and established global data sharing principles, ethics to respect privacy and confidentiality. There are procedures to anonymize and de-identify datasets before sharing. Data sharing from the center happens within the institutes (internal), within the country (national) and data sharing with international collaborators. Processing data sharing requests are entertained following EPHI's data sharing guidelines. The guideline can also be used to facilitate data sharing to the center/receiving data to NDMC repository from research institutes, NGOs, government agencies, private consultancy firms, academicians and from researchers when they do not have their own. The unit evaluates data sharing requests submitted to the director or the deputy directors' office or on the online system and its proposals detailing the objective and outcomes of the analysis. The unit avoids unnecessary delays in the data sharing process as much as possible by ensuring close follow up, delegating responsibility and establishing accountability mechanisms. This unit works with national and international research institutes on data sharing rules and regulations to maintain national interest on research data driven development of the country.

Creating national and continental health data hub is another responsibility of the unit aligned with nation and continental governance structures and standards. The national data hub includes regional health offices, regional public health institutes, HDSS, MoH, NGOs and Universities. The unit

considers creating continental data hub, aspires to serve the eastern African region, Africa CDC and the African continent at large.

Setting standards for identifying best-fit data exchange applications and interoperability bus is another activity of the unit. Interoperability ensures real-time data and report exchange between sources, data storage and analysis, and data security. The standards to be developed may include but not limited to 1) Develop and execution of terminology/vocabulary to address the ability to represent concepts in an unambiguous manner between a sender and receiver 2) Define data content standards, data transport standards, data privacy and security standards 3) Develop and execute data and related policy, proclamation, regulations, directives and guidelines, frameworks, standard operating procedures (SOPs). In the interoperability, data architecture, indicators and minimum standards need to be defined to clarify the mapping and archiving process of both institutional and population based data sources, arranged and interconnected with defined criteria or standards using FAIR (Findable, Accessible, Interoperable and Reusable) principles.

Creating electronic online data collection platforms for prospective data collection from the field synchronize with tablets and other electronic data capture is part of the unit's responsibility (Fig 6). The common platforms the EPHI researcher used are REDCap, CISPro, DHIS2 and ODK. The platform can be used for monitoring the research/project activities; support data quality checks and allows data management activities to be undertaken by individuals depending on their roles in the project.

Building strong and innovative data infrastructures and systems including hardware, software, networks and platforms have been an integral part of the case team to ensure expandable storage, sustainable and highly secured systems to achieve its national and continental roles and responsibilities. The unit has a multidisciplinary high caliber, committed and highly motivated experts capable of transforming the unit. To capacitate the staff, various trainings are given including research ethics, research methods and so also forth. The unit considers the need to improve data use culture through promotion, advocacy and incentives, "data campaigns and assigning national health data day", developing data use strategy with defined monitoring schemes and evidence quality standardization procedures.

Moreover, the unit archives all EPHI researches published in reputable journal digitize and archive hard copy years' old, historic and precious documents to facilitate easy access, and reuse, which can also serve as a backup and to build a data repository rich in historic and varied health and health-related data (Fig 6). The unit is responsible to support the establishment of strong health data systems at the regional health bureaus, regional public health institute and HDSS.

Specific objectives of DRG case team

- *Mapping and archiving prospective and retrospective data sets at national and sub national level*
- *Developing metadata for archived data sets,*
- *Catalogue and index health and health-related data using standard systems*

- *Create digital health data repository and tracking system*
- *Digitization/automation of data systems and regular update with data dashboards*
- *Establish health data governance systems and structures*
- *Make health data/information systems interoperable and interconnected with interoperability architecture within EPHI and across the region.*
- *Capacity building and technology transfer among different data actors*
- *Improve data use culture through advocacy and promotion*
- *Strengthen collaboration and engagement with HDSS, Local Universities, ACDC, IHME, BMGF, ABReN, FMoH, Health Bureau, NPHI*
- *Establish standards to assess the data quality of health data archived within the national repository,*
- *Create a national and continental health data hub/data repository with data backup and recovery, for seamless data sharing between diverse endpoints.*
- *Establish advanced data infrastructure standard data warehouse and, building standard data security, backup and recovery systems*
- *Digitize and archive hard copy years old, historic and precious documents*
- *Archive EPHI's scientific publications*

Data Analytics, Modeling and Visualization (DAV) unit

The goal of this unit is to transform health data analytics as well as outputs and result presentations using cutting-edge techniques, methods and applications that blend epidemiological, mathematical and statistical theories and rigorous techniques, modelling, forecasting, integrated analysis, heterogeneous and geospatial analysis (Figure 7). This is crucial because the conventional data analytic approaches are inadequate to the unprecedented volume of large and unstructured health and health related datasets. Analysing such big datasets require wrangling, scraping, creating, and managing; applying advanced statistical and mathematical methods; application of data science methods to reveal features of large and complex health data to draw conclusions from the data. Summarizing and visualizing using digital platforms is an effective way for easy and timely communication of analytic outputs, which in turn facilitates easy understanding and interpretation by users.

There is a constant increment in health and health related data. Owing to innovations and advances in biomedical and computational sciences, hitherto less valued varied data sources including satellite, GPS, telecom, climate, data from wearable devices, and machine readable data are becoming important source of health data. These voluminous fast velocity and big data of varied source as much as they present an opportunity, they also pose challenges to the conventional health data analytics. Moreover, as data are becoming deeper and richer with new sources of data generated using new technologies and sensors every now and then, our ability to harness and leverage useful knowledge from these data are critical to accelerate discoveries and innovations that can impact public health. This would require building Data Science and analytic capacities on machine learning/ artificial intelligence, modelling, forecasting and big data analytics.

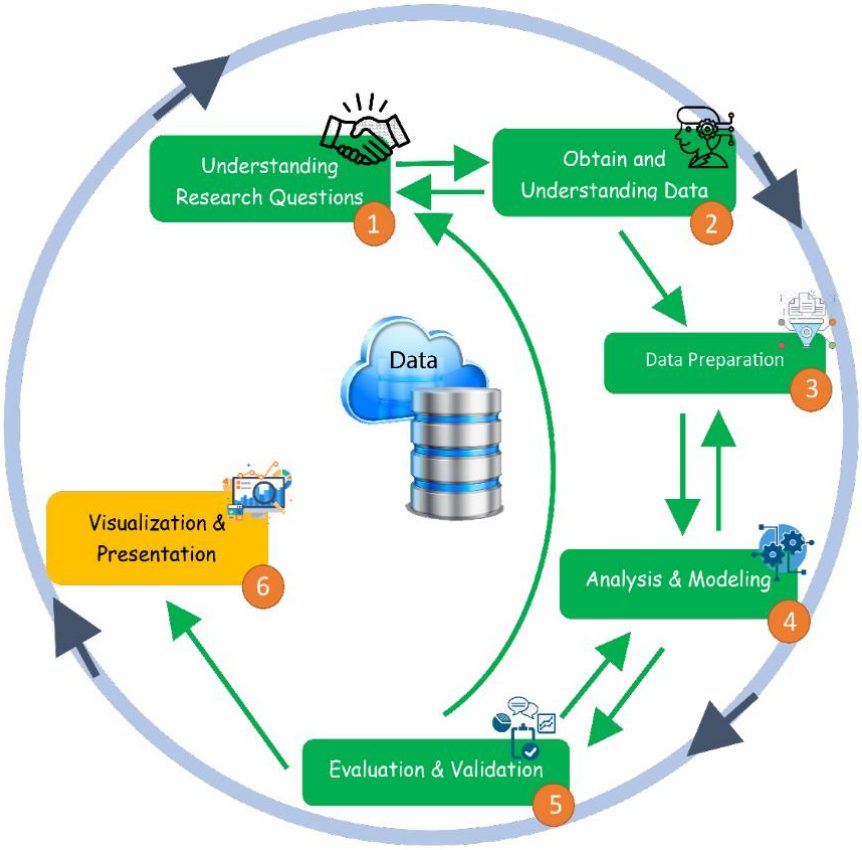


Figure 7: Flow diagram of data analytic, modelling and visualization unit

Innovative and robust computation and visualization approaches for high-dimensional health data, while bringing novel statistical and mathematical methods that can improve inference on health data is imperative for the unit. At the same time developing new ideas that can lessen bias and reduce variance in particular area is another important consideration of the unit. For this the unit identify, design, develop and execute several analytical platforms that fit multiple data sources. The analytic platforms are enabled with data visualization modules to facilitate easy understanding of trends, outliers, and patterns on the health and health related data (Figure 7). Moreover, developing web based interactive platforms with varied visualization galleries; simple to use and openly accessible is a crucial step for the unit to create a culture of making data-driven solutions for health challenges; for quantifying and presenting health loss from different diseases, injuries and risk factors; to rapidly characterizing, identifying and estimate disease parameters and predicting the outcomes and to assist health decision makers.

To match with the aforementioned demands on data analytic systems and techniques the unit has adopted improved technologies and cutting edge analytic methods for processing, analysing and visualizing health data. In order to build local capacity to harness data science for health, to ensure its sustainability and scale up, the unit has developed short-term basic and advanced data science for in-service online and face-to-face trainings. The training intends to fill knowledge and skill gaps in the application of data science for public health data at local, national and continental level. Moreover,

fellowship and internship programs are integral part of the unit's activity to attract high calibre experts, to tap on their expertise and to ensure sustainability and scale of the unit's initiatives.

Specific objectives of Data Analytics, Modelling and Visualization (DAV) unit

- *Apply data science, Machine Learning (ML)/Artificial Intelligence (AI), big data analytics techniques for heterogeneous, voluminous and big health data*
- *Advance health data analytics, modeling, forecasting, integrated analysis and geospatial analysis for heterogeneous data including epidemiological, clinical, evaluation, biomedical, laboratory, climate and other data through development, customization, adoption and application of advanced statistical, GIS, Climate, Epidemiological and Mathematical methods/models*
- *Developing all causes age specific mortality model for the country which project mortality trends since 1990 and forecasting across location and gender.*
- *Developing infectious disease models for emerging as COVID 19, those on elimination target as Malaria and HIV/AIDS and other reemerging as Cholera using data from diverse sources including epidemiology, economic, clinical, climate, satellite and GPS.*
- *Maximizing the use and utilization of local health datasets through the generation of extensive data quality assessment reports and guidelines for advanced health data analytics.*
- *Developing and maintaining interactive health data analytic platforms public health intelligence for sub-national, national and continental consumption.*
- *Developing Python health package (PyEhealth Package) for Ethiopia to provide easy access to different data analytic and machine-learning techniques*
- *Developing national health Geo-portal*
- *Building epidemiological and climate models for predicting outbreak occurrence to support responses including early warning, preparedness and plan, mitigation, prevention, control and elimination strategies.*
- *Supporting system automation and digitization work of the institute, the center and the team.*
- *Building public health data science capacity within the center, at national and continental levels through short-term accredited training with training manuals and curricula on basics of health data science, and advanced data science.*
- *Launching Fellowship and internship programs to attract high calibre experts, to tap on their expertise and to ensure sustainability and scale of the unit's initiatives,*
- *Building bio-statistical and epidemiological analytics, research methods, modeling and data science capacities to support EPHI researchers, MoH technical experts, academicians and graduate students as well as through specialized training and seminar within the institute, in Ethiopia and in the region*
- *Providing a scientific platform for advocating scientific analytic methodologies, and developed platforms*
- *Application of geospatial technologies and techniques for systematic management of geospatial data*

- *Modeling effects of climate variability and change on disease burden and on opportunities and effectiveness in the public health response*
- *Computing and mapping Human Comfort Index*
- *Developing health and climate atlas*
- *Creating standard geospatial data for analysis purpose through enhancing collected GIS data archived within the center and giving feedback for GIS data generate on the needed GIS attributes to be included during data collection*
- *Developing and implementing geospatial health data sharing policy*
- *Developing need assessment reports, System Requirement Specifications (SRSs), guidelines SOPs, documentation and methodologies to guide the unit's activities and to facilitate scale up of the initiatives.*

Evidence Synthesis and Translation (EST) unit

The ultimate goal of the unit is to support evidence informed decision-making, policy analysis and public health practices in Ethiopia and beyond. The major activities of the unit are prioritization of national health evidence demand; generation and synthesis of demand-driven high-quality evidences; health policy analysis; evidence translation and dissemination, and evidence use tracking. The unit intends to maximize evidence use at all levels to inform decision and promote the culture of evidence-based decision-making and practice. It aims at improving evidence synthesis and policy analysis through systematic reviews, and application of advanced data analytics, modelling and forecasting statistical and data science techniques using various data sources archived by the data repository and governance unit of the center.

The unit sets criteria to identify topics for analysis, areas that require evidence and areas where there are data gaps. Issues identified by MoH high-level decision makers requiring evidence to inform their day-to-day decisions often get priority. Prioritization criteria are evidence demand for policy and program launch/revision, magnitude and severity of the issue, availability of data, availability of resources and feasibility to undertake the analysis among others. The unit annually conducts, prioritizes and releases priority thematic topics/areas for evidence generation to direct the center's investment and to draw annual action plan. Moreover, the unit works closely with the DRG unit to map the data, the data sources and to review the data for prioritized topics.

The unit follows different approaches to get lists of priority topics within the center and beyond. These are written and/or in-person communication with MoH, local research institutes, health policy makers, individual researchers, professional associations, institutional review boards, funding organizations and others to get their priority list. A need assessment tool composed of closed and open questions is used to collect the list of evidence priorities in each targeted organization as well as to track their culture of evidence use. Moreover, the unit advises and facilitates research institutes and agencies to register their research areas prospectively, promote collection of primary data on data scarce priority topics of having national relevance, and facilitate data availability and accessibility for the center. The unit actively engages in 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 leads evidence synthesis activities internally, and it also coordinates and facilitates evidence synthesis endeavors within and outside of NDMC/EPHI. Synthesizing evidence to evaluate the impact of health policies and programs in promoting health, and preventing and controlling diseases requires real-time data from health economics, demography, and epidemiology and disease burden perspectives. The scope of evidence synthesis by the unit covers all aspects of health issues including communicable, non-communicable, reproductive, maternal, newborn and child health, nutrition, injuries, disasters, biomedical, behavioral, social determinants, health emergency, clinical and health systems. The unit also synthesizes evidence for early warning, mitigation, prevention, control and response of pandemics, epidemics and other public health emergencies.

The unit undertake policy analysis, scrutinize health promotion and disease prevention strategies; track and monitor progress made in HSTP, GTP, SDG and other national, continental and global targets. The focus areas of the center includes synthesizing evidence on universal health coverage, health extension program, primary health care, essential health service packages, and evaluating the national public health status and health care delivery through the use of economic evaluation, trend analysis, systematic reviews, and modeling techniques among others. In addition, the unit is also responsible for synthesizing biomedical research and basic science data available at EPHI and other research institutes. These activities are interlinked with the other units of the center.

Evidence translation activities of the unit include developing appropriate policy translation platforms and materials. Communication materials include peer-reviewed publications, policy/evidence briefs, web-based communications, preparing blogs, newsletters, press release and media briefs. The unit capitalizes on conventional and up to date evidence translation platforms including webpage, visualization, dashboard, social media, mainstream media, scientific evidence dissemination forums and reportable journals.

Together with the Burden of Disease Unit, the EST unit organizes manuscript writing, dissemination and scientific workshops. Establishing and strengthening strong partnership and collaboration is a key to the success of the unit. To this end the unit is building strong engagement team having commendable research communication skills. The unit invests heavily in forging collaborative partnership within and outside of the country to optimize its activities and outputs as well as to secure joint funding.

Specific objectives of EST unit

- *Develop and revise roadmaps/guidelines for national health evidence priority setting, evidence synthesis, and evidence translation;*
- *Conduct annual evidence demand assessment at MoH, Regional Health Bureau, partners and stakeholders;*
- *Facilitate the prioritization of national health problems for evidence synthesis through review of scientific and program documents and consultative workshops;*

- *Identify possible national hot/public health emergency issues.*
- *Prepare a cost-effectiveness analysis (CEA) database (registry) Produced CEA registry for use in African/South East Asian countries*
- *Develop protocol/term of reference on evidence synthesis priorities to guide data mapping, organization, integration, and analysis;*
- *Setting national health priorities for evidence synthesis*
- *Synthesizing evidence on identified health priorities*
- *Tracking and monitoring progress made in HSTP, GTP, SDG and other national, continental and global targets.*
- *Synthesizing evidence on universal health coverage, health extension program, primary health care, essential health service packages, and evaluating the national public health status and health care delivery through the use of economic evaluation, trend analysis, systematic reviews, and modeling techniques among others.*
- *Synthesizing evidence from biomedical and basic science research data available at EPHI and other research institutes.*
- *Enhance health policy analysis and informed decision making*
- *Facilitate visualization/dashboard use*
- *Produce evidence briefs, issue briefs, manuscripts and peer-reviewed publications;*
- *Disseminate evidences through different communication outlets (workshop, broadcasted media, and scientific conferences) to reach out wider audience;*
- *Facilitate evidence use for decision by MoH, RHB and partners;*
- *Establish evidence use tracking mechanism for regular tracking of evidence use*
- *Tracking, verifying, and measuring the use of evidence for decision, policy framework and public health practice*
- *Advancing evidence translation procedures and activities*
- *Conduct advocacy on the culture of evidence use*
- *Developing working guidelines and standard for the unit*
- *Establish collaboration with international /national institutions' having expertise in health priority setting, evidence prioritization and evidence translation for capacity building (short and long-term trainings) and technical support*

Burden of Disease unit

This unit builds strong foundation for improving the validity and reliability of burden of disease estimates by coordinating national GBD collaborative efforts and aims to play a leading role in Africa. Evidence based public health policy and practice are at the core in tracking and monitoring health progress, population health, demographic process and outcomes and achievement. Available evidence provides common indicators, which are critical elements for monitoring, tracking and evaluation across location, years, gender and age.

In collaboration with the Global Burden of Disease (GBD) study at IHME, University of Washington, Ministry of Health, in-country universities and research institutes, and the burden of disease

collaborator the unit support comprehensive and comparable national and subnational burden of disease quantification efforts using available and accessible health and health related data for Ethiopia. The unit is working to produce valid and reliable estimates in the country, across regions and cities; to show health inequalities in socio-economic, population and demography, and access to health care across regions and cities and districts, to help efficient utilization of limited health resources for priority areas.

Burden of disease estimates have been used as an evidence base to revise the national Essential Health Service Package, to develop National Communicable Diseases strategies and interventions, to monitor and evaluate HSTP II with its M&E framework and indicators, to evaluate health progress in the country, to ban all advertising of alcoholic drinks and forbade smoking near public places, to introduce a car-free day in major Ethiopian cities to promote physical exercise for the prevention of communicable diseases. Currently, more than 369 specific diseases and conditions, and more than 87 health risk factors both at national and sub-national levels for Ethiopia from 1990 to 2019 are quantified. It has used 1,057 distinct data sources that include census, demographic surveillance, household surveys, diseases registry, health service utilization, disease notification, and other data sources. Moreover, the burden of disease, injury and risk factor quantification provides estimates on life expectancy, health adjusted life expectancy, fertility, socio-demographic index (composite indicator consists of income, education and fertility). It also quantifies all cause and specific causes of death, incidence and prevalence of diseases, Years of Life Lost (YLL), Years Lived with Disabilities (YLD), Disability-Adjusted Life Years (DALYs) by cause, age, sex and years, and health risk factors' prevalence attributable health loss, life expectancy gain through decomposition methods.

The BoD unit also focuses on collecting relevant data from surveys and surveillance systems in collaboration with local institutions and international institutes. In collaboration with MoH and Universities the unit has identified following research priorities.to be undertaken Conducting post-census cause of death survey or sample registration system and population based morbidity surveys, strengthen DHIS2 and Health and Demographic Surveillance Systems (HDSS) for evaluating and contextualizing the GBD Study estimates, for undertaking triangulated analysis for profile analyses, monitoring SDGs and HTSP indicators Ethiopia's progress towards achieving the health sector transformation plan and sustainable development goals can only be monitored and evaluated using updated indicators. Evidence and indicators are generated from available data. Triangulated available data are good sources of strong and reliable indicators that can guide and monitor healthcare decision-making, teaching and research.
Furthermore, the creation of good environment for teaching and research is highly dependent on available evidence.

Specific objectives of burden of disease unit

- *Develop and customize innovative burden of disease theories and concepts, methods and techniques*
- *Develop and execute national and sub-national burden of disease implementation working guidelines*
- *Provide national, sub-national and local burden of disease, and risk factor estimates*

- *Provide burden of disease estimates for national and sub-national SDG and HSTP indicators*
- *Produce annual national and sub-national health atlas, epidemiological disease profiles*
- *Provide strategic support to MOH and partners on burden of disease issues.*
- *Provide support to in-country universities, Regional Health Bureaus, regional public Health Institutes and regional public health laboratories on burden of disease related issues*
- *Strengthen national and international burden of disease collaboration*
- *Serve as sub-Saharan Africa burden of disease regional hub in collaboration with Africa CDC, National Public Health Institutes in Africa, WHO and others*
- *Develop manuscripts and evidence briefs using GBD and other national data sources*
- *Provide updated annual burden of disease estimates for National Health Account and National Drug and Logistic data triangulation*
- *Triangulate and synthesis national burden of disease estimates with UN, World Bank and other estimate sources and national research outputs*

Chapter IV: NDMC Progresses and milestones

The center has made commendable progresses in several areas

Leadership and governance of the center

The NDMC leadership and governance encompasses EPHI Management, NDMC lead and case team leads. The center is directly accountable to EPHI's director general. The center has a core team composed of the coordinator of the center, NDMC advisor and the four case team leads. Each staff has stake in making decisions pertaining to their roles, responsibilities and assignments at different levels, in the planning, executing and reporting of activities.

Data Repository and Governance

The center has established strong data governance structures and systems including revising the 2016 EPHI's data management and sharing guidelines to govern not only data sharing and access but also the overall data systems at EPHI. In August 2019, EPHI management has endorsed the revised data management and sharing guidelines in line with the new structure of EHPI, NDMC's structure, functions and standards. Before the establishment of NDMC, for each research/surveillance undertaking, the PI should avail server ensure that data security and storage system are in place, while the IT case team supports data collection endeavors by creating and synchronizing data collection tools. Following its establishment, the NDMC ensures that all the necessary systems and infrastructures are in place to support data collection, archiving, sharing, access and submission in accordance with the 2019 revised guidelines. The center has been developing data quality framework to validate the quality of collected data and to give feedback for improving data quality before actual collection of data. Develop metadata standard and conducted interoperability assessment. The NDMC is heavily engaged in developing health data governance directive in collaboration with MoH's plan, policy and monitoring and evaluation directorate. Once approved by the MoH, the directive will help to govern health data sharing, access, and use and pave the way for open access for heath data.

Mapped health and health related data sources; these activities were undertaken in three phases

Phase I*: Mapping of data within EPHI using triangulated approach and obtaining the data. Being an evidence generation wing for the MOH, EPHI is responsible to undertake national and local researches, surveys, and surveillance. EPHI directorates generate research, surveys and surveillance data; public health emergency data and laboratory data. In phase I, the data mapping involved 1) EPHI's Scientific and Ethical Review office, which gives approval for any research undertaking of the institute, the MOH and many partners to get list of approved researches 2) Plan, Monitoring and Evaluation department of the institute, which track progress of each and every department of the institute including research undertakings to get list of planned and completed researches and surveillance undertakings of the institute 3) All directorates of the institute that undertake research, surveys and surveillance; public health emergency and laboratory directorates collecting routine data to get the list of researches and routine data collection undertaken. Based on the lists, data generating directorates and investigators were approached to facilitate data submission to the national health data repository.*

Phase II*; Mapping of data sources outside of EPHI and obtaining the data. Phase II data mapping started in 2019, whereby 43 local and international NGOs based in Addis Ababa, MoH, the CHAMPS project in Haromaya University and SIP project, metrology agency, policy reports on road traffic accident were addressed. Of these 33 of the NGOs', CHAMPS Ethiopia, MoH, SIP project, metrology data & policy reports on road traffic accident have been shared their data and the rest are underway.*
Phase III*; Mapping of data sources outside of Addis Ababa and those not covered in phase II. First a list of organization has been developed from internet search, exploring technical reports and articles from published researches. These are Regional health bureaus, universities, 10 local and international NGO which was not covered in the first round mapping, agencies having GIS data, private consultancies professional associations, Ethiopia cancer society were addressed. Of these Amhara, Oromia, Sidama and SNNP health offices, Amhara, Oromia and SNNP public health institutes, MERQ consultancy, Ethiopian cancer society data and GIS data have shared us large amount of surveillance, research and routine data to the national health data repository. In total 81% of NGOs and 67% of regional health bureaus/public health institutes have shared their data to the national repository.*
Archived datasets, EPHI publications, technical reports, and guidelines: A total of 310 datasets have been archived in the repository. Over 1700 articles published by EPHI staff in reportable scientific journals dating back to the 1940s have been archived in the system. Several project technical reports and NDMC working documents including guidelines, protocols and standard operating procedures have been archived in the system.
Created metadata: all datasets archived in the national repository have metadata (i.e description of the datasets) to facilitate dataset search, retrieval, access, sharing and use. A total of 264 metadata has been created as of July 15, 2021.

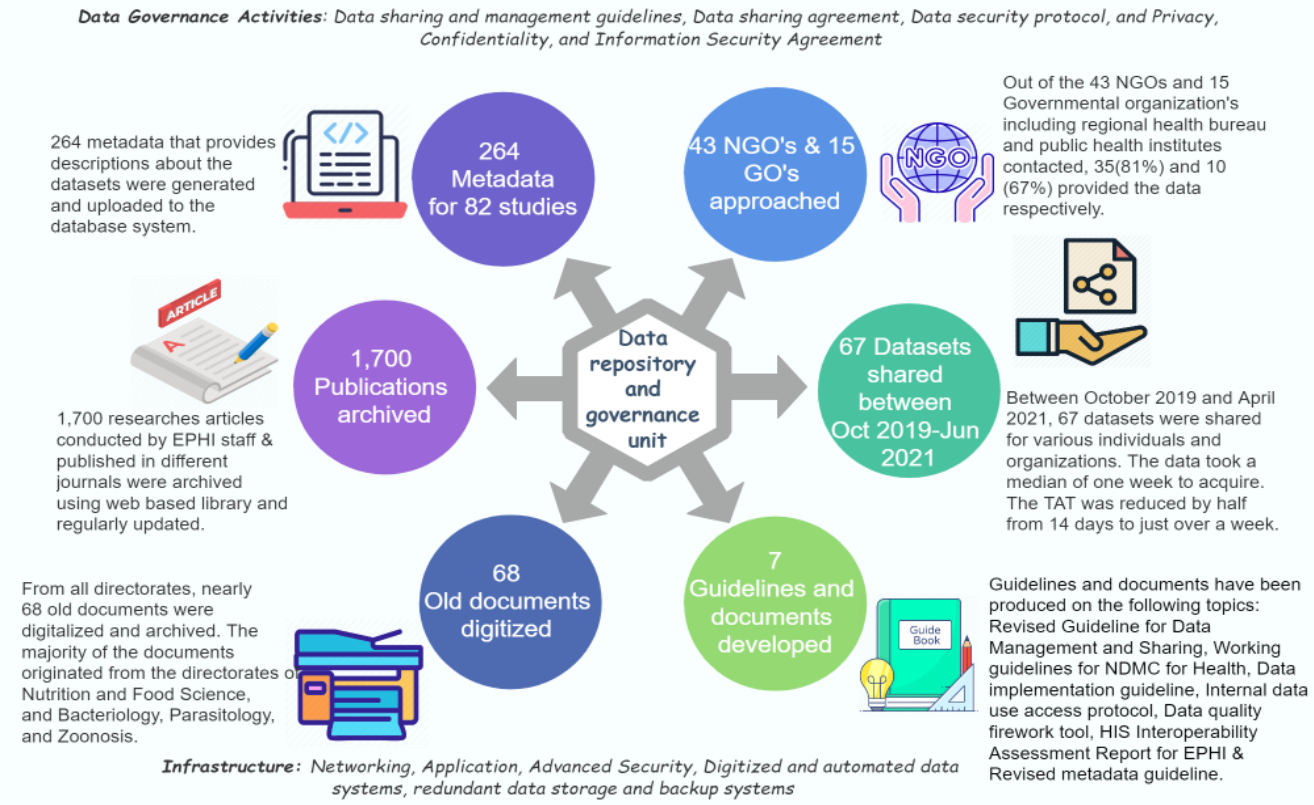


Figure 8, Data Repository and Governance team performance

Created secured data share: Health data are often collected from human subjects and are by nature sensitive with some confidential and private information. To ensure confidentiality NDMC share only data with no personal identifier (de-identified and/or anonymized). Moreover, the center established a highly secured web based application to share encrypted health data. Currently, data request and sharing is undertaken on this secured web platform, where the data requester is given with usernames and passwords in a separate email to access the data from the web or to submit the data when the request is from EPHI/NDMC. Expiry date and time to access or submit the data is set on the system. Data sharing: in total 71 data sharing requests have been submitted to NDMC since 2019, where the center starts to share data. Of which 67 of the requested data have been shared. Data sharing turnaround time has reduced from a Median of 13 days in the 2020 to a Median of 5 days in 2021. The figure below, shows

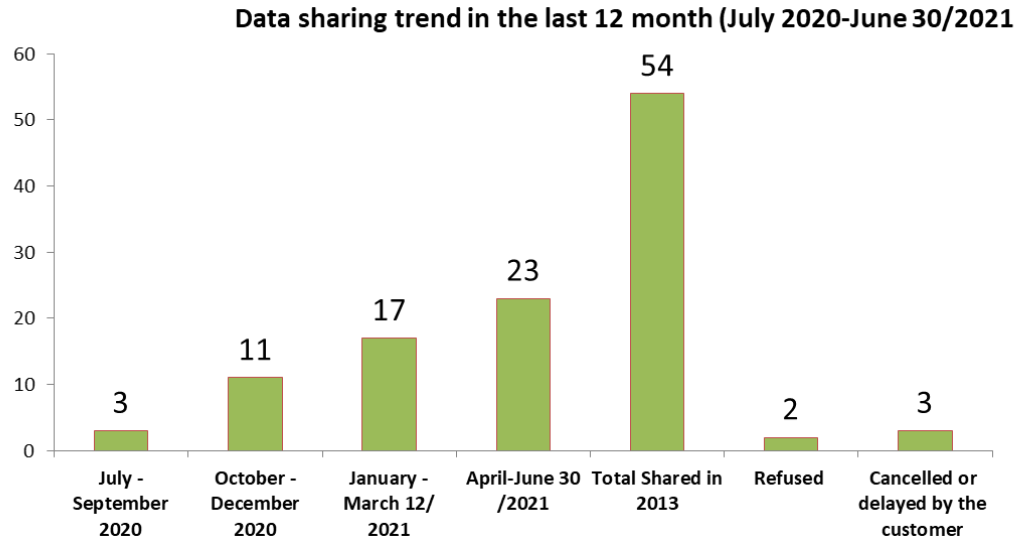


Figure 9: Data sharing trends from July 2020 to June 2021

Developed prospective data collection platforms: NDMC has developed digital platforms to facilitate prospective data archiving, data management and improve data governance. The platforms support electronic data collection from the filed using tablets and mobile phone; facilitate data archiving and storage; simplify data sharing and access; support data management (by making users to have defined roles); facilitate analysis; data visualization, dashboard creation and many more. EPHI's and MoH's commonly used systems as REDCap, DHIS 2, CISPro and ODK are incorporated in the platforms. These platforms are an opportunity for EPHI researcher having limited finance to tap on to ensure safe, secure and reliable data collection and storage. The platforms are secured web application to manage and administer cross-sectional and longitudinal researches, surveillance and surveys. The platforms support to initiate, plan, monitor, track and close research and its multiple workflows for smooth operation of a research. The platforms provide several integrated modules to do data quality check, generate reports with various format, online and offline data collection, and more. The integration of data collection and visualization platforms facilitates real time reporting, easy monitoring and progress tracking.

Developed online data repository and tracking system. All the aforementioned functionalities are integrated in a web based digital platform, called Research Tracking and Data Base System (RDTS). https://rtds.ephi.gov.et/public/

Data Analytics, Modeling and Visualization

The unit has accomplished the following activities

Developing strong analytic systems, capacity and expertize: the unit has developed analytic capacities to use Python, R programming, as well as STATA, SPSS statistical techniques, Epidemiological models as SEIR; GIS and climate data analytics. The unit has developed several web based interactive data analytic platforms blending mathematical, statistical, epidemiological, climate models.

Conducting several data analytic work: Using EDHS data, the center has conducted descriptive analyses on the trends and determinants of child health and child mortality across regions, age, wealth index and education. Childhood mortality SDG and HSTP II targets attainment have been modeled and forecasted with varying intervention coverage levels. Using 2016 EmONC data, availability, utilization and quality of EmONC and routine services delivery, coverage of MNCH services, and maternal morbidities were estimated. The team has also produced thematic maps in areas of covid-19 cases, GWD distribution, health facility distribution and accessibility map, conducting geospatial data quality assessment and report generation.

Launched Health Data Analytics and Visualization Hub (H-DAV) digital platform: This platform contains the following essential elements

- A platform for comparing and presenting diseases and risk factors patterns and trends associated with common childhood diseases;
- A platform for examining, comparing and presenting various causes of death and mortality rates among children under five; a module for assessing and presenting the availability, utilization and quality of EmONC and routine delivery services in Ethiopia;
- A platform for assessing and presenting the attainment of health-related goals set in SDG and HSTP II on priority health issues i.e Maternal Mortality, Under 5 mortality, Infant Mortality, Neonatal mortality and skilled birth attendance.

Produced numerous health-related geospatial analysis results: to generate thematic maps for providing information on the spatial distribution of local burden of diseases; for presenting COVID-19 spatial data analysis and risk mapping results; and for providing information on the spatial distribution of health facilities in Ethiopia.

Engaged in big initiatives and collaborative analytic works: with many local and international collaborators and partners to create an experience-sharing platform on the developments, applications and validations of advanced statistical and mathematical models, and data science techniques. Few of these activities are

- Developing an integrated mortality model for all age groups, sex, and locations.
- Developing platforms for detecting and forecasting infectious diseases using epidemiological and environmental data at different levels.

- Developing data science methods for identifying major factors contributing to common child health problems that are significantly contributing to the unprecedented neonatal and under-five deaths.
- Produced preliminary result on the effect of climate variability and air pollution factors on public health was generated.
- Generated different data quality assessment reports and correction guidelines, for both structured and unstructured health-related datasets.

COVID 19 epidemic modeling: Following the COVID 19 outbreak, the center has dived into COVID 19 modeling, as infectious disease modeling and disease intelligence is one of the objective of the center. The model uses surveillance data, behavioral data on non-pharmaceutical interventions, data on COVID 19 vaccination and health systems capacity, and other parameters from published sources. The center uses hybrid models i.e mathematical, epidemiological and statistical to improve infectious disease modelling and forecasting of COVID 19 progression across age, across regions, across gender and to forecast the peak time.

Developed Health Python package libraries, to provide easy access to different data analytic and machine-learning techniques; to help public health and health researchers to synthesis, and utilize evidence generation methods using data science applications.

Built visualization platforms and dashboards: all NDMC analytic outputs are integrated with interactive visualization platforms for easy access and to maximize use of the estimates at all levels. Interactive visualization platforms/dashboards have been developed for EPHI projects as GASHIARO project and for HERAMS : https://vizhub.ephi.gov.et/

Evidence Synthesis and Translation

Identified priority evidence gaps: through communication with MoH decision makers, health policy makers, individual researchers and funding organizations and through the review of policy, strategic and program documents, the center has identified evidence gaps at the start of the fiscal year.

Synthesized strong evidence for the identified evidence gaps to support decision at MoH and EPHI:

Evidence synthesis involved all the units of the center, collaborators and researchers within and outside of EHPI. Over the three years, 33 evidence briefs and 10 peer reviewed publications in reputable journals have been produced. The number of evidence briefs produced by the center has shown significant increase over the years. Being a new center, no publication was made in the first year. Moreover, the center generates evidences on national emergency issues and agendas. In 2020, COVID 19 and health benefits of GERD were prioritized as national emergency and agenda. In those efforts, three strong evidences on GERD were produced in July 2020. Similarly, evidence generation activities on GERD are undergoing to commemorate the second GERD filling.

Table 1: Evidence briefs and publications produced by NDMC from 2018 to 2021

Year	Evidence briefs	Publications	Manuscripts	Conference presentations
July 2018 to June 2019	6	3	6	4

July 2019 to June 2020	10	3	10	4
July 2020 to June 2021	17	4	15	3
Total from 2018- June 2021	33	10	21	10

Improved evidence translation: to inform decisions and practice: To facilitate evidence translation or to support evidence based decision, the unit prepares two page summary evidences, called evidence brief, for busy decision and policy makers to provide them key findings, which highlights program or policy implications. This is primarily intended to MoH, EPHI and other relevant decision makers. Evidence briefs have been communicated to MoH, EPHI and partners to foster evidence-informed decision. Scientific publications are other evidence translation platforms to reach out to the wider scientific community, academicians and researchers. In addition to publications, presentation on scientific congress and conferences has been undertaken as shown in table 1. To commemorate the first GERD filling, the center organized a workshop to disseminate evidence on the health impact of GERD which was attended by Dr. Lia Tadesse (Health Minister) as keynote speaker, Dr. Ebba Abata (General Director of EPHI) as opening remark speaker, and other high ranking officials and GERD negotiators. A follow up discussion was also held on Fana broadcasting corporate television program with two NDMC experts.

Burden of Disease

The center has produced national and subnational burden of disease (GBD) estimates in 2017 and 2019 in collaboration with the IHME. Following the funding from the BMGF that intends to produce national and sub-national burden of disease estimates and to improve its validity and use, sub-national disease burden estimates were produced in 2019 for the first time. The center has momentous contribution in reviewing the first sub-national estimates, in discussing methodologies, coordinating burden of disease collaborators, writing scientific manuscripts and facilitating evidence use for decisions.

Collaborations

Being one of the key strategic objectives of the center, collaboration has at most value at NDMC. It encompasses collaboration with local, national and international governmental and non-governmental organization; researchers; universities and funding agencies. Major collaboration areas are data sharing, evidence synthesis, evidence translation, data systems building and capacity building. Following its establishment the center has established strong collaborations with International Association of National Public Health Institutes (IANPHI) at Emory University linked with the CHAMPS Ethiopia project, which is undertaken under the auspices of Haromaya University. Here the CHAMPS Ethiopia project share project data and the NDMC/EPHI ensure on data to action, i.e maximizing the use of CHAMPS findings for policy and high level decisions by MoH and other stakeholders.

The center has signed collaborative agreements with 10 local universities that have Health and Demographic Surveillance Sites (HDSS) with the aim to improve the data systems at the sites, to share

data, to maximize evidence generation and use. With the University of Gondor and Addis Ababa University, the center collaborates to improve its data science initiatives, where data science fellows of the program will be given real data and real challenge to apply their knowledge and skills. Moreover, experience sharing; jointly seek for funding and other capacity building endeavors. The center has been collaborating with regional health bureaus and regional public health institutes to share data, to strengthen their data system, and for the center to play a coordinating role for improving the validity of the data collected at the local levels. The center has also collaborated with diaspora groups including People to People (P2P) and Australia Based Research Network (ABReN) to strengthen data systems of the center, analytics capacity and to generate strong policy relevant evidence to supports high level decision. Collaboration has been established with UNICEF, Mary Stops, MERQ consultancy, University of Bergen and DAI. The Harvard University projects the center has been collaborating are the HASeT project and Disease Control Priority.

Funding

The center receives modest finance from Ministry of Finance and Economy. This finance is too little for the magnanimous vision, mission and activities of the center. From the outset the center has been engaged into searching for competitive grants collaborating with local and international partners to secure fund to achieve its ambitious goal of transforming the health data system in Ethiopia and advancing health data analytics and to be a center for excellence.

In the first year of its establishment, the center has secured funding from IANPHI amounting 158,000 USD to support the Data-to-Action part of the CHAMPS, Ethiopia project.

In the second year of its establishment, the center has secured 6.2 million USD from the Bill and Melinda Gates Foundation (BMGF) in collaboration with University of Washington, Institute for Health Metrics and Evaluation (IHME). This fund is intended to improve the validity and reliability of national and sub-national disease burden estimates and to build relevant capacity for national sub-national burden of disease collaborative analysis.

In the third year of its establishment, the center has got 20 million USD funding from the World Bank as part of a bigger EPHI-ACDC-Zambia project with the aim to create interconnected and interoperable emergency surveillance systems for real time reporting and data sharing across the nation; to interconnect the Eastern African region and to create interactive infectious disease analytic platform to play a role of being a center for excellence in disease intelligence in Africa.

Capacity and system building

Human Resource Development:

The center has implemented various modalities for building human resource capacity and development.

Capacity building through hiring: Overall, the center has hired multidisciplinary high caliber experts. Currently, the center has a total of 36 staff, 4 senior (PhD holders), 28 Master holders and 04 BSc holders. The professional mix include public health, epidemiology, engineers, health economics, computation, programming, climate data experts, epidemiologic data experts, (bio)statisticians, demographer, data scientist, database administrators, server and storage administrators, communication specialist, full stack, child health experts, web admin and GIS experts.

Capacity building through short term training: As some of the required skills are not readily available in the market, NDMC staffs are required to attend online courses, attend call meetings, and experience sharing to fill knowledge and skill gaps. These include introductory courses on the basics of health research and epidemiology, courses on human research ethics, courses on Global burden of diseases and good clinical practice courses. The center provides short term training on GBD for MoH and EPHI researchers, program people and on the basics of public health data science and advanced data science.

Establishing fellowship programs: The fellowship programs include post-doctoral fellowship targets experts who have completed their PhD; public health fellowship targets experts who have completed their MSc/MPh/MA; while the Data Science fellowship target MSc student who wish to apply Data Science techniques and tools in undertaking their graduate research work.

Developing short term training modules for health data science: The center has developed the basics of Health Data Science module for face-to-face and online training in collaboration with EHPH training centers, involving five high-level data science experts from Addis Ababa University, Jimma University, and University of Gondor and from PsP (10 Academy) and is in the process to will accredit the training. The first batch of the training is planned to be started in November 2021. The training is intended to build local data analytic capacity, to ensure sustainability, to foster innovation and scientific advance and to ensure scale up of the centers data science initiative.

Developing working guidelines and protocols: to systematize and standardize its day-to-day works, the center has developed several guiding documents including, standard operating procedures, data analytics guidelines, evidence translation guidelines, and fellowship guide.

Building digital data infrastructure and architecture

Building strong digital technologies and techniques are critical for the center, to create advanced data systems, to transform data analytics, to manage information and knowledge. These include the tools used to produce, archive, store, process, analyze, share and exchange data/information and synthesize evidence. At the outset of the NDMC's establishment, the institute's ICT infrastructure was found to be limited and unable to support the centers enormous digital data infrastructure demand and the center's functions. The center has undertaken an IT need assessment and an IT audit with support from the Ministry of Science and Technology experts.

Upgrading IT infrastructure

Guided by the assessment and audit reports, EPHI and the center have made huge investment to upgrade the ICT infrastructure to accommodate the center's need for the state of the art technologies to support its warehouse and advanced analytics and computational demand. To accommodate future enormous demand on storage, high computation and integration of multiple data sets of varying dimensions using Artificial Intelligence/machine learning and technological advances, the has center huge finance to establish state of the art data center. The data center is going to be housed in the newly constructed EPHI complex, where the center has submitted requirements for the data center to be considered in the design of the complex the MoH is drafting. Moreover, the center is considering having a disaster recovery site, outside of EPHI's compound, preferably outside of Addis in a different geological zone.

Upgrading IT network: EPHI procured required networking devices (Cisco ASA firewall, Cisco distribution switch, web security appliance and hot spot management appliance) to upgrade the previous flat network to hierarchical network architecture (layered approach (access layer, collapsed core layer and edge layer)). This architecture improves the security, availability and reliability of information exchange between intended parties. VLAN technologies have been implemented to separate traffics between departments within the institutes. The internet capacity has also increased from 60Mbps to 500Mbps to make data accessing smooth and free of congestion.

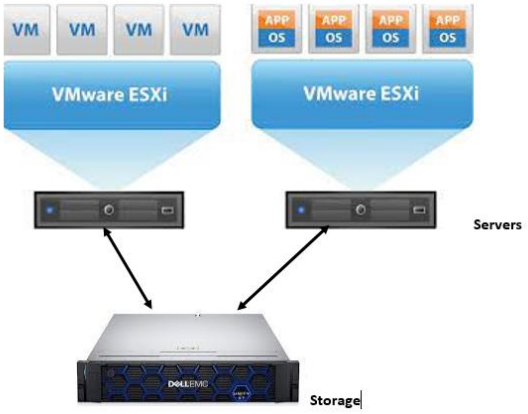
Upgrading servers and storage: Investments have been made to procure powerful high end servers and storage. The center has implemented sever and hardware virtualization (configuring one physical server to be multiple servers for intended purposes) for improved resources management and administration. To improve availability, two servers are clustered and configured for virtualization. These clustered servers are integrated with the storage server to improve the storage capacity of the servers and to isolate the actual data from the system software. This contributes to the safety of the data in case of server hardware and software failure.

Current NDMC ICT infrastructure: NDMC has state-of-the-art information technology infrastructure to support the data centric works of the center, including software, high performance and reliable data storage, flexible and extensible virtual environments, improved internet access and supporting network infrastructure,

1. *Major software applications available at EPHI include REDCap, in house web applications (repository, data tracking database systems, journal system, Next cloud, Solar winds, GIS/ArcGIS/QGIS, Stata, Python, R, Power Bi, Google Colab, Matlab, DS Algorithm Modules, High level visual representation with JS frameworks and libraries, R, Sequel Pro, Anaconda, Git, SAS, SPSS, Veeam backup and replication, ESXi hyper vision and Antivirus software.*
2. *Highly-scalable and robust data storage systems currently offering >80 Terabyte of high-performance disk and >4 Terabyte of archival storage. This file system allows for seamless growth as research needs change and expand, as well as multiple access points or redundancy for Linux and Windows servers and desktops, increasing the speed with which data processing can occur.*
3. *Archival storage file system supported by daily back-ups of all archived data. A supplementary archival storage system for sensitive, identifiable data is also provided and secured via role-based access controls.*
4. *Flexible and extensible virtual server environment supporting >150 virtual machines. The virtualized environment is supported on its own highly-parallelized storage and compute array and is backed up regularly.*
5. *A family of >8 high performance database servers running state-of-the-art relational database implementations used to store and display results, with over 10 Terabytes of solid state disk.*
6. *All of these systems are supported by a scalable and robust network within the EPHI Data Center having >50 gigabits per second high performance switches deployed in cisco composite network architecture model. All interconnected resources are available to all staff and secured behind rigorous firewall and user-access controls.*

7. *All the database servers have been replicated within the site every two hours between the production and the replica server. It is planned to place the replicated off site to also support disaster.*

Current EPHI ICT architecture



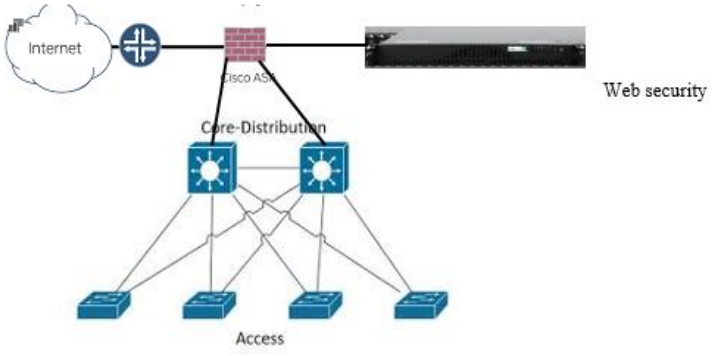


Figure 8: A. Storage architecture *B. Current network infrastructure*

Developed mmultiple digital visualization platforms and dashboards: to support activities of different directorates of the institute

Developing digital Enterprise Resource Planning (ERP) solutions: to automate operations of the institute

Annex

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