



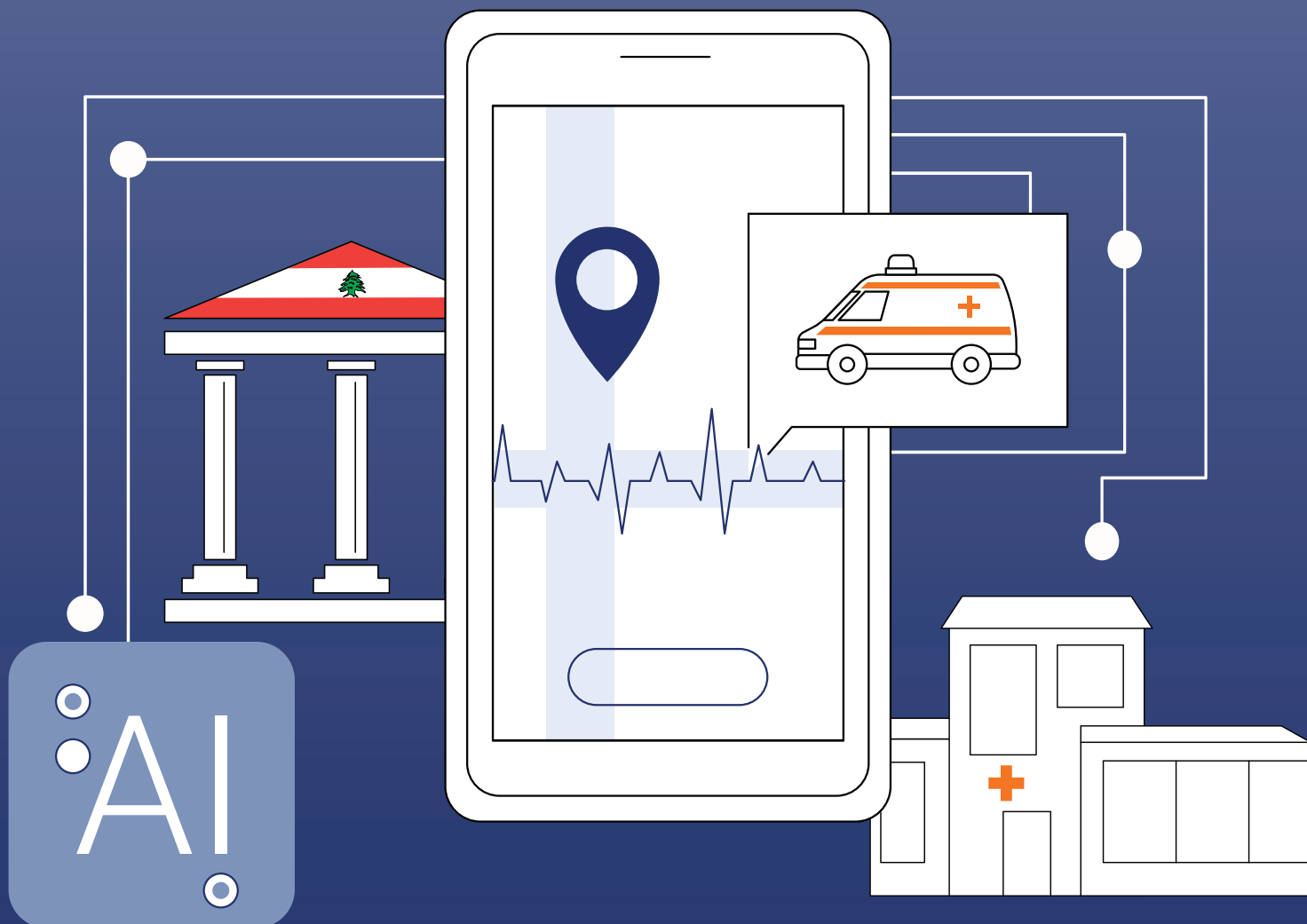
MENA OBSERVATORY
ON RESPONSIBLE AI
مركز الشرق الأوسط وشمال أفريقيا للأبحاث الإصطناعية المسؤولة

Governing Responsible Artificial Intelligence and Data
in the Middle East and North Africa (MENA)

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Health Data Governance during Emergencies in Lebanon



March 2025

**HEALTH DATA GOVERNANCE LANDSCAPE:
A FOUNDATION FOR RESPONSIBLE USE OF AI
DURING EMERGENCIES IN LEBANON**

Case Study

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ACRONYMS AND ABBREVIATIONS

AFP	Acute flaccid paralysis
AI	Artificial Intelligence
DMBOK	Data Management Body of Knowledge
ESU	Epidemiological Surveillance Unit
GDPR	General Data Protection Regulation
HIPAA	Health Insurance Portability and Accountability Act
HIS	Health Information System
ICT	Information and communication technology
ISF	Internal Security Forces
IT	Information Technology
K-PHC	Karagueusian Primary Healthcare Center
LRC	Lebanese Red Cross
MoJ	Ministry of Justice
MoPH	Ministry of Public Health
NIST	National Institute of Standards and Technology
OMSAR	Office of the Minister of State for Administrative Reform
OOP	Out-of-pocket expenditures
PHCs	Primary Healthcare Centers
RHUH	Rafic Hariri University Hospital
UN	United Nations
UNHCR	United Nations High Commissioner for Refugees
WHO	World Health Organization

I. INTRODUCTION – CONTEXT AND PURPOSE OF THE STUDY

The COVID-19 pandemic has introduced unprecedented pressures to healthcare systems worldwide.¹ It also uncovered fundamental gaps in emergency preparedness and response, including weak surveillance, early warning, and routine information systems.² This emergency highlighted the importance of redesigning health system arrangements to endure better future public health shocks.³ Strengthening data and information systems is a crucial aspect of building resilience in health systems.⁴ This entails establishing mature early warning and surveillance systems, and routinely updated health information systems that focus on essential health services, social registries, and data-sharing protocols across actors.⁵ More recently, there has been a concerted effort to integrate artificial intelligence (AI) into healthcare systems. This integration holds the potential to enhance the efficiency, accuracy, and responsiveness of healthcare services, further improving overall health outcomes.^{6,7} In addition, AI technologies play a promising role in crisis management and disaster medicine, including rapid identification of medical emergencies, analysis of large datasets to evaluate disaster impact, guidance for search and rescue efforts, traffic management during emergencies, real-time data communication to emergency teams, risk assessment and prediction, and optimization of hospital resources, among others.⁸

Beyond the impact of COVID-19, Lebanon grapples with compounded humanitarian, political, economic, and health crises including a recent cholera outbreak. These crises strained the healthcare system and revealed gaps in health data governance in Lebanon. Key issues included the lack of unified health data governance structures at a national level and across institutions. These data governance system challenges hinder the ability of the health sector to manage the use of data and artificial intelligence responsibly. Weak data governance also strains the existing fragmented healthcare sector and deters its efficiency.

Responsible use of artificial intelligence and rigorous data governance policies were shown to improve accountability, efficiency in healthcare systems, protection of citizen rights, and accessibility of healthcare services, particularly in low-resource settings.⁹ Given the recent challenges faced by the health sector and Lebanon's susceptibility to emergencies, it is crucial to assess current data governance practices during emergencies. Identifying challenges and opportunities in this context is essential for (1) developing a more resilient health system, (2) establishing a foundation for effective health policy reforms, and (3) informing the responsible use of AI in health systems with a focus on data governance as a fundamental input to AI governance.

II. RESEARCH OBJECTIVE

The objective of this case study is to produce a situation analysis of health data governance practices during emergencies in Lebanon. This analysis will involve an in-depth examination of current processes, protocols, challenges, and potential avenues for enhancing health data governance in the country. The case study will also present context-specific policy options that would enable effective governance of health data systems and responsible use of artificial intelligence (AI) during emergencies.

III. BACKGROUND

The Lebanese healthcare system has historically relied on data to inform national decisions with the surge of epidemiological, geographical, and socioeconomic surveys and studies since the 1950s. Not only did these studies generate data that informed decision-making when it comes

1 Mjaess, G., Karam, A., Chebel, R., Abi Tayeh, G., & Aoun, F. (2021). COVID-19, the economic crisis, and the Beirut blast: what 2020 meant to the Lebanese health-care system. *Eastern Mediterranean Health Journal*, 27, 535-537. <https://doi.org/10.26719/2021.27.6.535>

2 WHO. (2021). Tracking continuity of health services during the COVID-19 pandemic. <https://www.who.int/teams/integrated-health-services/monitoring-health-services/national-pulse-survey-on-continuity-of-essential-health-services-during-the-covid-19-pandemic/dashboard>

3 Haldane, V., & Morgan, G. T. (2021). From resilient to transient health systems: the deep transformation of health systems in response to the COVID-19 pandemic. *Health policy and planning*, 36(1), 134-135. <https://doi.org/10.1093/heapol/czaa169>

4 Gebremeskel AT, Otu A, Abimbola S, Yaya S. Building resilient health systems in Africa beyond the COVID-19 pandemic response. *BMJ Glob Health*. 2021 Jun;6(6):e006108. doi: 10.1136/bmjgh-2021-006108. PMID: 34183330; PMCID: PMC8245280.

5 WHO. (2017). Integrating rehabilitation into health systems-Information. *Health Information Systems (who.int)*

6 World Economic Form. (2023). Emerging tech, like AI, is poised to make healthcare more accurate, accessible and sustainable. <https://www.weforum.org/agenda/2023/06/emerging-tech-like-ai-are-poised-to-make-healthcare-more-accurate-accessible-and-sustainable/>

7 Alowais, S.A., Alghamdi, S.S., Alsuhbany, N. et al. Revolutionizing healthcare: the role of artificial intelligence in clinical practice. *BMC Med Educ* 23, 689 (2023). <https://doi.org/10.1186/s12909-023-04698-z>

8 Frontiers. (2024). Artificial Intelligence in Emergency Health Services. <https://www.frontiersin.org/research-topics/60250/artificial-intelligence-in-emergency-health-services#:~:text=Artificial%20intelligence%20technologies%20have%20a,disasters%2C%20improving%20and%20guiding%20search>

9 Baltaxe, E., Czypionka, T., Kraus, M., Reiss, M., Askildsen, J. E., Grenkovic, R., Lindén, T. S., Pitter, J. G., Rutten-van Molken, M., Solans, O., Stokes, J., Struckmann, V., Roca, J., & Cano, I. (2019). Digital Health Transformation of Integrated Care in Europe: Overarching Analysis of 17 Integrated Care Programs. *Journal of medical Internet research*, 21(9), e14956. <https://doi.org/10.2196/14956>

to defining the sector's needs and priorities but also facilitated the monitoring and evaluation of the health system performance indicators, such as out-of-pocket expenditure (OOP), mortality rates, and others.^{10,11}

Towards a digitized health sector

The importance of data in informing decisions of the health sector at a national level led the Ministry of Public Health (MoPH) to initiate the journey of managing these vast amounts of national data through the digitalization of the health system. The ministry started by digitizing data collection and storage processes in 2003 through the creation of a unified database that included the information of all citizens benefiting from public funds coverage in the country.¹² In 2013, the MoPH launched the National E-health program that aimed at enhancing the quality of care through the use of information and communications technology. These efforts continued in 2017 with the launching of the Meditrack-Pharmaceuticals 2D barcode initiative that aimed to track medications across the traceability supply chain, control illegal drugs, speed up medication recall from the market, and ensure safe access to medications.¹³ Following the compounded crises that the country has endured and the profound impact on the health sector, it became evident that the global trajectory in building more resilient health systems involves the establishment of robust data-driven digital health systems. In response to this reality, the ministry intensified its commitment to digitizing the health sector through the recent launch of "Empowering Lebanon's Healthcare System: A Vision for Digital Health Transformation" earlier in 2023. This vision highlights the challenges in Lebanon's healthcare sector that necessitate digital transformation, such as inadequate infrastructure, financial implications, data governance problems, low digital literacy rates, and the absence of standardized protocols and interoperability frameworks leading to the fragmentation of

health data.^{14,15,16} The envisioned plan strongly emphasizes utilizing digital solutions to enhance healthcare outcomes, presenting an opportune moment to leverage AI deployment in the future. By integrating AI into these digital healthcare solutions, healthcare services can be augmented across various dimensions. This includes improving efficiency, coordinating care, enhancing patient safety and healthcare quality, increasing access to healthcare services, improving population health outcomes, reducing health services costs, and fortifying preparedness for emerging health challenges.¹⁷

Health Data Availability and Quality

The availability and accessibility to high-quality data during emergency events not only is crucial for effective emergency management but also acts as an indicator of data governance status in a given country. Given the history of Lebanon in emergencies, the MoPH reactivated the Epidemiological Surveillance Unit (ESU) after the civil war in 1995. The ESU is responsible for managing the national surveillance system regarding communicable diseases, monitoring epidemiological alerts, carrying out on-site investigations and analytical epidemiological studies, providing feedback for healthcare providers, and training them on surveillance tools. Following the Communicable Diseases Law issued in 1957, healthcare providers and healthcare facilities are requested to report to the MoPH-selected communicable diseases.¹⁸ Initially, surveillance reporting was paper-based which caused delays in the receiving of information and consequently delays in outbreak detection and response, primarily due to the hierarchy of data flow within the system. In 2017, MoPH started the process of transitioning the surveillance reporting into a web-based electronic platform to ensure the availability of real-time information

10 Abou-Abbas, L., Nasser, Z., Baaklini, M., Cheaito, L., Karout, J., Sweidan, H., . . . Hassan, H. (2022). COVID-19 mortality surveillance in Lebanon. *Scientific Reports*, 12(1), 14639. Retrieved from <https://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med22&AN=36030277>

11 Lerberghe, W.V, M. A., Kronfol.N., (2018). THE COLLABORATIVE GOVERNANCE OF LEBANON'S HEALTH SECTOR: Twenty Years of efforts to transform health system performance. Retrieved from <https://www.moph.gov.lb/userfiles/files/Programs%26Projects/PSO/The-Collaborative-Governance-of-Lebanons-Health-Sector.pdf>

12 Lerberghe, W.V, M. A., Kronfol.N., (2018). THE COLLABORATIVE GOVERNANCE OF LEBANON'S HEALTH SECTOR: Twenty Years of efforts to transform health system performance. Retrieved from <https://www.moph.gov.lb/userfiles/files/Programs%26Projects/PSO/The-Collaborative-Governance-of-Lebanons-Health-Sector.pdf>

13 MoPH. (2017). MediTrack Project- Track and Trace System for Pharmaceuticals. Retrieved from <https://www.moph.gov.lb/en/Pages/6/15089/meditrack-project-track-trace-medicines-through-the-2d-barcode>

14 Asmar, M. K., Yeretizian, J. S., & Rady, A. (2016). Compiling comprehensive national health statistics in a fragmented health information system: lessons learned from Lebanon. *Eastern Mediterranean Health Journal*, 22(1), 52-57. Retrieved from <https://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=pnm3&AN=27117651>

15 Badr, N., & Kosremelli Asmar, M. (2016). Quality of Data in Lebanese Healthcare Databases: Literature Review and Empirical Investigation. *Lecture Notes in Computer Science*.

16 Youssef, D., Yaghi, A., Jouny, A., Abou-Abbas, L., Chammaa, H., & Ghosn, N. (2022). Converting the existing disease surveillance from a paper-based to an electronic-based system using district health information system (DHIS-2) for real-time information: the Lebanese experience. *BMC Health Services Research*, 22(1), 395. Retrieved from <https://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med21&AN=35337327>

17 MOPH. (2023). Empowering Lebanon's Healthcare System: A Vision for Digital Health Transformation. <https://www.moph.gov.lb/en/Pages/0/70100/ vision-for-digital-health-transformation>

18 El Hage, S., Safi, S., Assouad, E., El Kareh, A., Mokled, E., & Salameh, P. (2022). Acute flaccid paralysis incidence rate and epidemiology in children in Lebanon: a rise in numbers in the post-vaccination and refugee crisis era. *African Health Sciences*, 22(2), 116-124. Retrieved from <https://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med22&AN=36407402>

to detect alerts and outbreaks.^{14,15,19} The surveillance system in Lebanon played an integral part in providing data for decision-makers and public health experts, especially during emergencies mainly during the Polio outbreak, the COVID-19 pandemic, and the Cholera outbreak.

To ensure rapid and swift response to potential Polio cases and in efforts to eradicate Polio in the country, MoPH endorsed the Acute Flaccid Paralysis (AFP) surveillance, which is a gold standard for poliomyelitis detection in 1994. This system reports each year the number of polio and non-polio AFP cases. Lebanon has passed through two waves of Polio alerts, the first one in 2003 with the importation of a case infected with a strain that was like that circulating in India, and the second was in 2013 with the outbreak of Polio in Syria. The vigilance of the surveillance system and the rapid response from MoPH in collaboration with different partners in intensifying the vaccination against Polio, succeeded in the absence of poliomyelitis cases in the country.²⁰ This highlights the need to replicate similar initiatives and mechanisms for other surveillance systems to ensure early detection of threats and rapid response to public health emergencies.

During the COVID-19 pandemic, the surveillance system played a crucial role as the primary source of official data issued by MoPH on the pandemic's progress. It reported morbidity and mortality cases through indicator and event-based surveillance, receiving reports from private and public healthcare facilities. Three main channels were utilized: (1) The communicable disease surveillance system; (2) The civil registration and vital statistics system, and (3) The administrative services reporting system.⁷ Event-based surveillance was used to supplement indicator surveillance systems in accumulating COVID-19 mortality data through various data sources like burial services or media screening. The burial services were requested to immediately report to the ESU team about mortalities caused by COVID-19. In addition, the burial services were obligated to share with the ESU team the deceased's personal information including contact information, such as name, date of birth, and phone number, as well as details related to the death event, the location and date of death. Moreover, the ESU team was responsible for the daily inspection of several data sources like the press news and social media posts to identify death cases. Additionally, the central ESU team was responsible

for data quality checks and detecting redundancy and incompleteness in reported data.²¹

The surveillance system was of essential use in the latest national public health emergency, the Cholera outbreak. Lebanon has not had any Cholera outbreaks in 30 years; however, in October 2022, the first case of cholera was detected. The outbreak spread rapidly and after one month in November 2022, the number of suspected cases reached 2,241 cases with 413 cases confirmed later. Due to the economic crisis, effective response to the Cholera outbreak became a challenge, that's why MoPH collaborated with different international partners such as WHO to respond to this public health emergency.^{22,23,24,18} The main focus of the response was to continue surveillance for the detection of any suspected cases to reduce avoidable morbidity and mortality, reduce the transmission of the disease in affected areas, and prevent and minimize the risk of transmission to high-risk areas. Lessons learned from the COVID-19 pandemic when it comes to data documentation, sharing, and multisectoral collaboration have led to the rapid response and containment of the outbreak.

The MoPH's adoption of a web-based electronic surveillance platform lays the groundwork for future AI integration. By digitizing surveillance systems, real-time information becomes more accessible, facilitating early detection of alerts and emergencies like the Polio, COVID-19, and Cholera outbreaks. AI can then serve as a powerful tool to analyze large datasets, identify patterns, and provide predictive analytics, enabling timely interventions during emergencies and allowing decision-makers to allocate resources more efficiently.

Health Data Sharing in Lebanon

To maximize the benefits of utilizing and analyzing health data for improved health outcomes, engaging in data sharing is essential. Data sharing facilitates a more profound understanding of health needs and challenges, particularly during emergencies. In addition, it presents a signifi-

19 Solidarites International. (2023). *Cholera Emergency in Lebanon*. Retrieved from <https://www.solidarites.org/en/live-from-the-field/emergency-cholera-au-libanon/>

20 MoPH. (2015). Acute Flaccid Paralysis surveillance guideline. https://www.moph.gov.lb/userfiles/files/Esu_resources/Esu_guidelines/g_afp_2015_e.pdf

21 Abou-Abbas, L., Nasser, Z., Baaklini, M., Cheaito, L., Karout, J., Sweidan, H., Jouni, A., Ghosn, N., & Hassan, H. (2022). COVID-19 mortality surveillance in Lebanon. *Scientific Reports*, 12(1), 14639. <https://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med22&AN=36030277>

22 Action Against Hunger. (2022). *Lebanon Cholera Emergency SITREP #4*. Retrieved from file:///C:/Users/zs70/Downloads/Action%20Against%20Hunger%20-%20Lebanon%20Cholera%20Emergency%20Sitrep%204%20(1).pdf

23 Al-Tammemi, A. B., & Sallam, M. (2023). The current cholera menace amid the war crisis in Syria and the economic crisis in Lebanon: A time for global solidarity. *New Microbes & New Infections*, 51, 101069. Retrieved from <https://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=pnm&AN=36593883>

24 Kassem, II, Osman, M., Jaafar, H., & El Omari, K. (2022). Refugee settlements, sewage pollution, COVID-19 and the unfolding cholera outbreak in Lebanon. *Journal of Travel Medicine*, 29(8), 27. Retrieved from <https://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med1&AN=36434781>

cant opportunity for AI adoption in healthcare. By sharing diverse datasets across healthcare institutions and organizations, AI systems can access a wealth of information necessary for robust analysis and predictive modeling. During emergencies and outbreaks, for instance, AI analytic tools can leverage shared health data to rapidly assess risks, allocate resources effectively, and guide response efforts. This can significantly improve emergency preparedness and response, ultimately saving lives and alleviating the impact of crises.

In Lebanon, the lack of data sharing and collaboration represented a huge obstacle in the context of health emergencies, especially during the COVID-19 pandemic. The Rafic Hariri University Hospital (RHUH), the largest Lebanese public hospital, was the only hospital assigned for diagnosing, isolating, and treating COVID-19 cases. This resulted in inaccurate estimations of COVID-19 spread within the community and hindered the ability to forecast trends in case numbers, consequently leading to decision-making based on inadequate information.²⁵

Health data protection in Lebanon

The presence of robust and rigorous data protection processes is an essential component of protecting people and their rights. When it comes to protecting health data, Lebanon has yet to issue a comprehensive law that would ensure that sensitive data, such as health data, is highly protected from any potential threats and breaches. The only law in the country that covers personal data protection is law no. 81/2018 “Electronic Transactions and Personal Data”. Many loopholes were identified in this law that render it incapable of protecting personal data in general and health data in specific. One loophole is in the fifth article of the law where the Ministry of Economy and Trade is the sole entity to provide access to personal data. This could lead to the exploitation of personal data, unlike other countries where independent entities are developed to authorize data protection. For example, in France and Tunisia, the data protection authority includes representatives from the parliament, judicial branch, multi-sector ministries, and private sector. Also, as per Article 97, the Ministry of Justice (MoJ) and MoPH are given access to the data stored and may allow private companies to access sensitive personal data based on their relationship with ministers. In addition, the purpose and processes for data col-

lection as per Article 87 remain vague.^{26,27} Data security is managed at different organizational levels, with measures to protect patients’ medical information, however, these measures lack standardization at a national level.²⁸

IV. OVERVIEW OF AI INITIATIVES IN HEALTHCARE IN LEBANON

In Lebanon, AI initiatives in healthcare primarily exist within the private sector. It is worth noting, however, that these initiatives operate in silos, resulting in fragmented efforts and limited scalability across the healthcare system. These initiatives include but are not limited to TrakMD (online platform for doctor discovery & appointment booking), eTobb (online platform that allows users to ask health related questions and get answers from doctors for free), Spike Diabetes Assistant (an app for monitoring lifestyle and managing diabetes), and AI in the screening & diagnosis of early lung cancer at Mount Lebanon Hospital University Medical Center.^{29,30} Overall, the aim of such initiatives is to enhance efficiency, accuracy, and accessibility in healthcare services, albeit within their respective spheres of operation. However, there is a need for greater collaboration and integration to realize the full potential of AI in transforming healthcare delivery across the country.

V. METHODOLOGY

A systematic review of the literature on health data governance during emergencies in Lebanon was conducted. This was done by developing a search strategy to examine existing literature on Medline, PubMed, and Google Scholar. The search aimed at highlighting the present health data policies, programs, and frameworks; available research on health data governance processes during emergencies in Lebanon; and the gaps in health data governance in periods of emergency (Annex 1). Findings from the literature search will identify gaps in health data

25 Abou Hassan, F. F., Bou Hamdan, M., Ali, F., & Melhem, N. M. (2023). Response to COVID-19 in Lebanon: update, challenges and lessons learned. *Epidemiology & Infection*, 151, e23. doi:10.1017/S0950268823000067

26 Halabi, M. (2021). *The Legal and regulatory challenges of making e-transactions a defining part of the Lebanese economy* Retrieved from https://laur.lau.edu.lb:8443/xmlui/bitstream/handle/10725/13746/Mirna_Mohamad_Halabi_Thesis_Redacted.pdf?sequence=1&isAllowed=y

27 Sofia, K. (2019). *Electronic transactions in Lebanon*. Retrieved from <http://hdl.handle.net/10725/10627>

28 Ghosn, N., Nasredine, A., Baddour, Y. M., Coulombier, D., & Nasserline, S. (2008). Electronic surveillance of outbreaks in Lebanon. *BMC Proc*, 2 Suppl 3(Suppl 3), S2. doi:10.1186/1753-6561-2-s3-s2

29 Tracxn. (2024). HealthTech Startups in Lebanon. Top 10 startups in HealthTech in Lebanon-Tracxn

30 MLHUMC. (2022). Artificial Intelligence- AI in the screening & diagnosis of Cancer at MLHUMC. Artificial intelligence - AI in the screening & diagnosis of cancer at MLHUMC - Mount Lebanon Hospital University Medical Center

SECTOR	ORGANIZATION
Public	Ministry of Public Health (MOPH)
	Internal Security Forces (ISF)
	Office of the Minister of State for Administrative Reform (OMSAR)
	Lebanese Army
Primary health centers (PHCs) and Dispensaries	Makhzoumi Foundation
	Karagheusian Primary Healthcare Center (K-PHC)
Private Sector	American University of Beirut Medical Center
	LAU Medical Center- Rizk Hospital
UN Agencies	Inter-agency Coordination - UNHCR
NGOs	Lebanese Red Cross (LRC)
	SMEX
Experts	Digital Transformation and cyber security expert
	Legal expert in Information and communication technology (ICT), IP/ ICT law

Table 1: Participated stakeholders with their corresponding sectors and organizations

governance during crises and will inform the stakeholder's interview guide.

Semi-structured interviews consultations were conducted with 17 key stakeholders to discuss and understand the health data cycle process, including data planning, collection, analysis, storage, sharing, usage, and lessons learned, as well as the challenges in health data governance and the responsible use of AI during emergencies. Purposeful sampling and snowballing were employed to select the stakeholders.

Stakeholders that participated in the key informant interviews included representatives from the public sector private sector, United Nations (UN) agencies, local and regional non-governmental organizations, legal experts, and cybersecurity and digital transformation experts (Table 1).

Data collection tools consisted of (1) interview questions and (2) a data catalogue developed by A2K4D. The interview guide consisted of general questions addressed to entities involved in delivering health services and collecting data. It also featured tailored questions designed for experts in the field. The questionnaire was divided into eight sections, that address data management, collection, analysis, storage, security, sharing and interoperability, monitoring, and evaluation, and lessons learned from previous emergencies with a focus on responsible use of AI (Annex 2) (Annex 3).

VI. THEORETICAL FRAMEWORK

A thorough review of available evidence was conducted to assess existing frameworks, principles, and components for health data governance. Renowned frameworks such as the Paul Namuag framework, the Data Management Body of Knowledge (DMBOK) framework, the WHO framework, and the Health Data Governance Principles endorsed by the World Bank were included in this review. After careful consideration, the "Health Data Governance Principles" was selected for evaluating health data governance in Lebanon (Figure 1).

The World Bank's Health Data Governance Principles serve as a foundational framework, incorporating a human rights and equity perspective into data utilization within and across health systems. Designed to strengthen and unify governance structures, policies, and regulations worldwide, this framework promotes equitable health data governance. In addition, it provides a platform for leveraging digital technologies (e.g., AI) and data to improve and protect the health and well-being of all individuals.

The "Health Data Governance Principles," revolves around three interconnected objectives:

Protect People: This component emphasizes the significance of safeguarding individuals, groups, and communities. It mainly focuses on ensuring data security, building trust in data systems, and

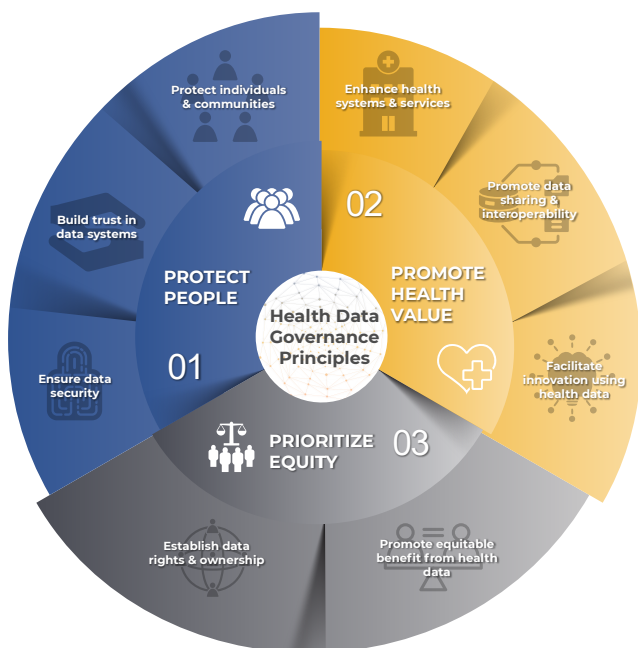


Figure 1: The Health Data Governance Principles framework.³¹

protecting individuals and communities alongside individual data rights.

Promote Health Value: This component aims to enhance overall health outcomes and healthcare delivery by addressing collective needs and benefits of public health systems. It primarily focuses on maximizing the value derived from health data through data sharing and interoperability, utilization of innovative technologies, and enhancement of health systems and services.

Prioritize Equity: Placing a strong emphasis on equity, this component ensures fair and equitable distribution of benefits arising from the use of data in health systems. It strives to address disparities among groups and individuals, striving for transparent delineation of data rights and ownership and equitable access to benefits from health data.

Given its comprehensive approach and global significance, this theoretical framework was adopted to systematically assess Lebanon's data governance structures and explore the integration of AI in its health system.

VII. FIELDWORK FINDINGS: EXISTING HEALTH DATA PRACTICES

Protect People

Data Collection and Quality

Protecting the people whether as individuals or communities during health data collection requires the availability of documented policies and procedures that would organize this process at the institutional level. These policies should cover the type of data to be collected, the purpose behind collecting data, and the consent form required before collecting data taking into consideration the specificities of marginalized groups and populations in the community (Figure 2).

Data Collection Policies and Processes

The presence of written policies and procedures that would define and regulate the process of data collection from the first encounter of the patient with the service provider until receiving the service was identified as a cornerstone for data collection. Nationally, MoPH has established inclusive health data collection processes for its platforms and applications. This inclusive data collection process takes into consideration the specificity of marginalized communities living in the country. This is evident in the new cancer platform that is designed to facilitate access of cancer patients to safe and authorized medications. Currently, the services provided through this platform are limited to Lebanese citizens, however, this will not be the case forever. The platform was created to serve all cancer patients residing in the country, that's why MoPH has created data collection processes specific for non- Lebanese on this application.

At the healthcare facilities level, specifically for primary health centers (PHCs) and hospitals, the development of these policies was a requirement in the accreditation program. These facilities were required to develop and document data collection policies that specify the type of data to be collected, who will collect the data, and how it will be collected. Yet, the data collection policies across these healthcare facilities failed to document the potential risks that individuals may encounter during data collection.

The COVID-19 pandemic has pushed some organizations to assess and redesign their data collection processes to overcome difficulties encountered during the pandemic. For example, in the wake of the Cholera outbreak following COVID-19, certain organizations started using digital technologies to collect data in particular

³¹ The World Bank's Health Data Governance Principles (<https://healthdatagovernance.org/principles/>), revisualised



Figure 2: This Figure shows the different pillars that were evaluated under the Protect the People principle.

settings, such as prisons. This transition helped to eliminate the need to manually transfer data from paper records to the central electronic system as was the case during the COVID-19 pandemic. The shift to digital data collection creates opportunities for future AI adoption by streamlining processes, enabling efficient analysis of large datasets, and enhancing data accuracy.

Consent Acquisition Before Collection

Consent, verbal or written, is crucial in data collection to safeguard both individuals and facilities. At primary health centers, verbal consent is typically obtained, as patients visiting these centers expect that personal and medical data will be collected before the provision of services. However, during outreach activities, campaigns, or research, PHCs require that a written consent is signed by the beneficiary or patient before

data collection. In hospitals, a signed written consent form is mandatory before admission, except in life-saving emergencies or cases of unconscious patients.

Type of Health Data Collection

In Lebanon, there is no standardization when it comes to the type of health data permitted to be collected from patients across different organizations. In healthcare facilities data collected can be broadly categorized into personal and medical data. Personal data includes the name, age, sex, and phone number while medical data includes information related to the medical history of a patient such as the history of surgeries, allergies, medications, chronic illnesses etc. It is worth mentioning that the COVID-19 pandemic has pushed many healthcare facilities to incorporate new elements, mainly related to

infectious diseases, into the type of data to be collected. These modifications were informed by advice from infectious diseases experts and aimed at effectively tracking and monitoring the progression of the pandemic.

During emergencies, similar information is gathered, though the documentation may be less detailed due to the urgency of the situation, as observed during the Beirut Port Blast. Across non-health facilities and organizations such as non-governmental organizations, there is no specific type of data to be collected from beneficiaries, whereby these organizations tend to collect personal information that is considered by data experts as beyond necessary.

The consequences of the lack of standards governing the type of data collected from individuals were evident during the COVID-19 pandemic specifically with the “MoPH Pass” platform used by MoPH. This platform was created to provide passes for travelers visiting Lebanon, however, the requested information to be shared on this platform was believed to be beyond what is required. Due to uncertainties regarding data protection measures within the MoPH Pass application, numerous travelers were hesitant to share sensitive information such as a passport copy, flight number, and address in Lebanon. Concerns about potential breaches of this information contributed to the reluctance of many individuals to provide these details.

The inconsistency in the collected data types undermines the country’s data governance. This issue could be addressed by establishing a centralized national data center responsible for supplying organizations with data tailored to their specific requirements.

The absence of standardized health data collection in Lebanon poses a challenge for future AI adoption. Without consistent data standards, AI algorithms may struggle to effectively analyze and interpret heterogeneous datasets, hindering their ability to generate accurate insights and provide effective recommendations. Additionally, discrepancies in data collection practices can lead to inconsistencies and biases in AI models, potentially impacting the quality and reliability of AI-driven healthcare interventions.

Data quality

Ensuring the high quality of collected data is crucial, as it directly influences its ability to inform decision-making and build trust in data systems. In Lebanon, a critical shortage in human resources coupled with political and economic restraints and a pandemic have compromised health data quality. During the pandemic, many citizens have felt reluctant to share all the required in-

formation creating several incomplete data sets and affecting the quality of data. This scenario presents a hurdle for AI adoption since such innovations heavily depend on standardized, high-quality data for optimal decision-making. Incomplete or inconsistent data may result in biased or erroneous outcomes when deploying AI models. Consequently, without standardized data collection procedures and continuous data quality assurance measures, AI adoption could be impeded, constraining its ability to significantly contribute to healthcare decision-making, research, and patient care both during and after health emergencies like the COVID-19 pandemic.

The foundation for ensuring data quality lies in the standardization of data collection procedures across various institutions. These standard procedures could be mandated by MoPH based on evidence and best practices and accompanied by rigorous monitoring and evaluation mechanisms. Notably, while these standards may exist at the institutional level, variations across these institutions persist due to the absence of national standardization.

Establishing these standards is the initial step to maintaining the quality of the collected data, but insufficient on its own. Equally important is the training of human resources on the application of these standardized procedures. In Lebanon, training is integrated into the onboarding process for recruits in their respective institutions to standardize the process of data collection. For instance, all staff of a primary health care center undergo training on the proper acquisition of vital signs ensuring uniform methodology and instilling confidence within the administration team regarding the accuracy of the vital data collected.

Regular quality evaluations of collected data are a vital factor in maintaining data integrity. Some institutions have established dedicated departments for routine data audits, where a random sample of medical files undergoes thorough examination. The focus is on assessing completeness, specifically regarding the presence of healthcare provider notes and comprehensive medical histories. Corrective actions are implemented to address and rectify any missing information or discrepancies identified during these audit procedures. When it comes to maintaining high-quality financial data, many facilities have resorted to external auditors that would ensure the integrity of the data.

Adopting digital systems enhanced the quality of data collected in many facilities. Digital systems are structured with an organized data entry method, requiring information to be entered in a specific order. This design prevents

users from advancing to other data categories if the current one is empty. Additionally, these systems feature embedded quality checks that automatically identify and flag any incorrect or defective data submissions, contributing to a robust data quality management process.

It is evident that high-quality data is indispensable for the successful integration of AI in healthcare. Flawed or low-quality data used to train and validate AI models can severely compromise the system's effectiveness and reliability. Through meticulous examinations of random medical file samples, for example, dedicated departments can pinpoint inconsistencies, errors, or biases which enable early detection and rectification of issues. Consequently, adopting similar measures enhances the overall quality and reliability of data utilized by AI applications to improve patient care, streamline diagnoses, and optimize treatment outcomes.

Data Storage

Protecting individuals and communities encompasses securing data storage mechanisms that are robust, reliable, and secure to protect the health data of citizens. In Lebanon, health data is stored either on physical storage servers or on a cloud storage. When storing data on storage servers, several backups of data were created on different servers in multiple locations. These storage servers are protected using several data storage processes from data encryption, to access control mechanisms, to firewalls and others. This choice of data storage was attributed to the weak internet infrastructure in the country that renders the internet connection unstable and unreliable, posing a risk to the accessibility to health data during regular days and, particularly, during emergencies. As for institutions that store their data in Clouds, they have adopted rigorous cybersecurity measures for the safety of their beneficiary's data. The implemented data storage mechanisms in the different health facilities be it physical servers or clouds have demonstrated their efficiency amid the COVID-19 pandemic. However, there was a specific occurrence related to the data gathered on COVID-19 vaccinations through the IMPACT platform. Data from this platform was initially stored on a cloud located outside the country, this raised concerns about the security and safety of the data. The reason was attributed to the fact that the Lebanese government does not have control over this data and its security and protection measures abide by the cloud host country. Political reasons were believed to be the real reason behind raising such concerns and to avoid a political conflict from escalating in the country, the government moved the data storage to servers in Ogero.

Data Security

Data security is a fundamental component of health data governance, encompassing technical and practical requirements that protect individuals and communities at large. This involves best practices, such as data anonymization and/or encryption, which play a critical role in safeguarding individuals' privacy. In Lebanon, most institutions employed such practices through (1) adopting data coding practices, (2) hiding sensitive information in patient files, and (3) de-identifying private patient data. During COVID-19, however, there was a concern with the IMPACT platform, with some stakeholders reporting that the data in this system failed to be encrypted jeopardizing the safety and security of sensitive data.

Apart from safeguarding sensitive information through data encryption and anonymity, institutions have to establish and respect comprehensive policies and procedures governing data access and utilization. In Lebanon, these policies and procedures are established across different institutions, where access to data is linked to the roles and responsibilities of the personnel. These policies ensured that only eligible personnel were granted access to either view, edit, manage, or handle data.

Data security threats are common and pressing issues that must be addressed to safeguard sensitive information. Several processes can be employed to prevent and mitigate data privacy risks. These can include legal interventions, such as implementing laws that carefully emphasize the need for high-level data protection with the best criteria such as the General Data Protection Regulation followed in Europe. This should be aligned with robust protection policies that explicitly describe data security best practices, including mitigation strategies, and are flexible enough to adapt to the evolving nature of innovative technologies and protection techniques. Codes of conduct and confidentiality agreements for personnel were considered as a preventative approach to these types of risks. Furthermore, implementing risk management, having alert systems, utilizing established cyber security frameworks (e.g., National Institute of Standards and Technology (NIST) framework), adopting advanced servers, firewalls, encrypted data, and pen-testing, as well as prioritizing training and capacity building workshops, and establishing an emergency disaster recovery system (e.g., multiple database locations) are additional processes for securing data and mitigating threat risks.

Ideally, when there is a breach of data, affected individuals and communities have the right

to be informed. In Lebanon, notifying affected individuals about potential data breaches was perceived as futile, mainly because the data cannot be recovered once it is leaked, so the focus should be directed towards the prevention of future breaches and enhancement of overall data security measures.

The presence of COVID-19 has yielded valuable lessons in the realm of data security. Before COVID-19, data management practices, including protection measures, were overlooked. The pandemic served as a wake-up call for many, as it made them more aware of the importance of data and its security. Although IMPACT was not perfect and its implementation was not as efficient in other countries, its creation was a critical milestone for Lebanon. This is mainly because the gaps and shortcomings of such intervention can serve as a guide for future data management and security interventions. Moreover, this inspired several institutions to adopt contingency plans for data protection and to conduct regular monitoring and evaluation of their data security systems. In addition, the pandemic served as a motive to advocate for the need for data security experts, as it unveiled a huge shortage of such critical professionals. The presence of data protection laws and policies appeared to be a more accepted priority after facing the repercussions of COVID-19 which necessitates the revision of law 81/2018 to strengthen data protection in the country.

Promote Health Value

Data Analysis

The data collected was used to guide decision-making within different institutions during health emergencies, specifically when it comes to (1) strategic planning and goal setting, and (2) the monitoring of an organization's progress.

Analyzing the gathered data empowered organizations to develop comprehensive strategic plans and set goals that yield positive effects on various operational aspects of the healthcare system. This can include an enhanced supply chain, a better allocation of resources, and an efficient management of the healthcare workforce, among others. For instance, the data collected provided critical information to better allocate and dispatch the health workforce in cases of emergencies by optimizing the deployment schedules and prioritizing high-impact areas. In addition, collected data acted as a critical pillar in informing budgetary concerns and financial decisions, specifically after the economic crisis and the devaluation of the national currency (LBP). During the COVID-19 pandemic, for example, the data collected drew

attention to the increase in the cost of managing patients requiring the implementation of institutional adjustments. Data collected played an important role in identifying community health trends to better inform the preparation of emergency preparedness plans and the planning of healthcare services provided.

Besides serving as a vital component in the strategic planning of organizations, regularly collected data is indispensable for monitoring and assessing progress toward specific healthcare goals and targets. Collected data could be used to advocate for necessary actions and resources to meet set goals, such as vaccination campaigns. Data analysis processes before, during, and after the COVID-19 pandemic, were not drastically changed, except that COVID-19 increased the focus on the surveillance of infectious diseases and the frequency of analyzing collected data (Figure 3).

AI has the potential to significantly enhance decision-making processes in healthcare using sophisticated data analysis functions. Through advanced analytics and predictive modeling, AI technologies can scrutinize extensive datasets to uncover patterns, trends, and correlations that may elude decision-makers. This capability facilitates more precise forecasting of healthcare requirements and highlights areas for system enhancement. Additionally, AI-powered decision support systems can furnish healthcare professionals and other key stakeholders with real-time interpretations and recommendations, enabling swift and informed decision-making, particularly in emergency situations.

Data Sharing and Interoperability

Data sharing and interoperability are fundamental components in any comprehensive system and healthcare framework, specifically in the event of emergencies. While data-sharing mechanisms may differ among institutions in the country, the majority of organizations indicated that they share data with MoPH, whether or not emergencies are ongoing. PHCs share data sharing with the MoPH through PHEN-ICS. During the COVID-19 pandemic, interoperability and data-sharing tools were placed across various sectors to coordinate response and patient management.

Data sharing and interoperability are mostly absent in Lebanon due to a series of critical shortcomings in existing data structures. The main challenge was the lack of well-defined standards and unified data exchange mechanisms for data sharing among institutions, especially hospitals, resulting in data redundancy across centers and missed opportunities for substantial data analysis. This issue was mostly accom-



Figure 3: This figure shows how institutions used data in informing their decisions

panied by the absence of a unique identifiers (ID) system, which has been proven to facilitate health data exchange, enforce data security, reduce redundancy, and enhance data quality. Interestingly, competitive factors, such as rivalry among medical institutions and the replacement of healthcare professionals, and socio-political factors, such as sectarianism, also impeded data sharing in the Lebanese context. Another significant issue that was commonly reported was the weakness of MoPH, in bridging interoperability across institutions and between fundamental platforms. Lastly, the insufficiency of financial resources and the limitations in the current infrastructure acted as significant gaps in data sharing and interoperability.

The lack of data sharing and interoperability in Lebanon poses a notable hurdle for potential AI implementation. Without standardized data structures and smooth data exchange mechanisms, AI models may face difficulties accessing and integrating diverse datasets efficiently. This fragmentation undermines the capacity to fully leverage AI technologies, which depend on comprehensive and interconnected data sources to produce precise observations and predictions. Consequently, the absence of data sharing and interoperability obstructs the adoption of AI solutions that have the poten-

tial to transform healthcare delivery, research, and decision-making procedures.

Amidst the current data-sharing challenges in health emergencies, opportunities are waiting to be seized. The digital health transformation vision, mostly based on lessons learned from COVID-19, has been released, and leveraging this strategy is a great opportunity to enhance data sharing and interoperability, particularly in the case of emergencies. Establishing standardized codes and procedures between different institutions was found to be an essential part of this transformation. It was further highlighted that founding a database at the level of the MoPH could serve a significant purpose in pooling data from multiple healthcare institutions, streamlining the flow of information, and ensuring better quality health data. This consolidation presents a critical opportunity for AI integration, as AI innovations can effectively analyze large, centralized datasets to derive informative insights, identify patterns, and enhance decision-making processes in healthcare delivery and policy formulation.

Artificial Intelligence and Data Governance

In the past few years, AI and machine learning have been increasingly recognized for their potential emerging roles in transforming the domain of health data governance. Due to the revolutionary nature of AI and its potential risks to

data privacy and other ethical concerns, varying perspectives regarding the enforcement and adherence of health data governance policies during the adoption of new technologies within institutions were expressed. While there is a general agreement that control measures are indispensable when adopting AI and similar technologies, there is hesitation to establish rigid, overarching regulations mainly due to the rapidly evolving nature of the innovation and technology sector. Hence, rather than focusing on policies and regulations at the levels of laws, there is a growing preference to strengthen existing data management regulations at the level of institutions. These institution-specific guidelines would draw inspiration from existing laws but would provide more flexibility, allowing institutions to adapt to the evolving landscape of AI and health data governance while ensuring responsible usage. While emerging technologies like AI offer the potential to streamline health data governance efforts, it remains crucial to recognize potential challenges associated with their integration within healthcare institutions. In this context, the most significant challenges were primarily identified as (1) ethical consideration and (2) a lack of trust in AI and related technologies. Ethical considerations, including data privacy and safety risks, were primary concerns when adopting AI in healthcare. Not being able to ensure the protection of patient data and maintaining data integrity can result in widespread distrust and vulnerability of health systems. Information bias is another challenge when it comes to the information and data that are being fed to the algorithms in the adopted AI systems. Lastly, the lack of trust in AI and related technologies can hinder their effective adoption. There is a need to build confidence in AI systems to utilize their full potential and overcome skepticism, with some of them emphasizing the critical roles of awareness, capacity building, and data security processes.

Prioritize Equity

Data Management

Health data governance policies with well-defined roles and responsibilities are essential in responding to health emergencies and safeguarding public health. These policies mainly aim to facilitate effective coordination, ensure rights and ownership of data, maintain data quality, ensure adherence to data security measures, and promote transparency and accountability in overall data management. Many data governance policies were found at the institutional level in Lebanon. Although policies may vary across institutions, all policies address issues related to data types, data-sharing procedures, and data access within the HIS. For exam-

ple, these policies guide nurses on which files they are permitted to access and review, in contrast to physicians who have distinct roles and responsibilities in data management. Although these policies are mostly in place, there is still room for improvement regarding the content and enforcement of such policies.

Establishing data rights and ownership is a necessity for the formulation of legislative and policy frameworks that align with evolving national, regional, and global standards. These frameworks should encompass clear definitions of ownership (such as health data being owned by the individuals or communities providing it) and associated rights (including the right to control data usage, the right to refuse participation in data collection, the right to remove data from a system, and the right to derive benefits from it). Understanding data ownership is critical to ensure data security, privacy, and responsible management, particularly during health emergencies. However, it was emphasized that legally individuals are entitled to own their data but this is far from reality.

The right to access data can be different from owning data. This means that some individuals/entities can have the privilege of viewing or retrieving data for a specific purpose without necessarily having full ownership or control over it. During health emergencies in Lebanon, the accessibility of health data seems to vary among institutions, mainly as a result of established institutional policies and regulations. This became apparent during the COVID-19 pandemic, where, in addition to the MoPH, other organizations, such as LRC, the Lebanese Civil Army, healthcare institutions, and even Ogero obtained access to health-related data from some sources. During the pandemic, for instance, the population's vaccination data was stored outside of Lebanon initially and then moved back to Ogero for data storage. However, a significant concern arose primarily regarding trust. Individuals raised questions about the composition of Ogero's workforce, and whether this entity had the capabilities to appropriately store and protect sensitive health-related data.

Data Rights and Ownership

Health data governance should be rooted in strong and clear data-related rights. Data ownership implies that individuals and communities have a right to know, determine, and control their data. Hence, institutions must ensure that the health data-related rights of individuals are always protected. Securing health data-related rights can be accomplished through actions such as seeking consent, educating patients about data ownership and rights, and ensuring

healthcare providers and other data custodians acknowledge and honor these rights.

Likewise, ensuring that health data provided in health emergencies is owned by individuals and communities is a cornerstone in the principle of prioritizing equity. Thus, it is essential to incorporate comprehensive data rights and ownership provisions into a legal framework. Established laws and regulations on data governance must take into account a clear definition of personal data, privacy, ownership, transparency, and processing. However, this is not the case in Lebanon, which unfortunately shows insufficient regard for data rights and ownership. The gravity of this issue can be reflected by the fact that when data was hijacked from a particular company, individuals were not informed about the loss of their data, the security measures in place, or any steps taken to enhance data protection.

Health data governance should align with, and take lessons from, well-established global and regional policies and regulations, such as the GDPR in Europe, to ensure best practices that protect individuals and their data. In Lebanon, adherence to these types of norms is purely optional, leading to the presence of institutions that either (1) follow alternative regional and global standards to guide their regulations or (2) neglect to align their policies with any well-established norms. Among those institutions that choose to adhere to regional and global norms, a lack of standardized guidance is apparent, with some entities adhering to European standards (GDPR) while others opt for American standards like the Health Insurance Portability and Accountability Act (HIPAA). This variation can lead to inconsistencies in national data rights and ownership efforts. Moreover, the fact that most institutions fail to align their data rights and ownership policies with regional and global norms, especially when Lebanon fails to have its own, has created an environment where even donors and international companies tend to overlook the privacy and safety of Lebanese data.

Health emergencies, such as COVID-19, are expected to impact several system domains, including data management, rights, and ownership. Nevertheless, in the context of Lebanon, no variations in the processes of data management, rights, and ownership were documented during and following the pandemic. Substantial uncertainties in data management procedures were highlighted that involved local authorities, including municipalities and other authorities in charge of crisis management. When data was requested from local authorities, difficulties were encountered in obtaining identifiers of positive cases mainly due to enforced data privacy regulations that prevented the disclosure of indi-

viduals' names. Consequently, municipalities attempted to change data management processes by accessing information through other channels, which was not only time-consuming but also somehow unethical. This delay, allowed infected individuals to move around freely, further exacerbating the national infectivity rate and affecting the public's health. This situation underscored the importance of striking a balance between accessing personal information during emergencies while respecting data protection, public welfare, and ethical principles for the greater good.

Data Analysis

During emergencies, the needs of marginalized groups tend to be overlooked which leads to an amplification of inequalities. Taking into consideration the needs of marginalized groups, such as refugees and people with disabilities, in decision-making processes during health emergencies is critical. Recognizing the needs of the most vulnerable and addressing inequality gaps was reported as a cornerstone of their organizations' visions. This was evident during the Cholera outbreak whereby vaccines were made available for marginalized people such as people in detentions and refugees living in informal settlements.

VIII. ANALYSIS AND TAKEAWAYS: DATA CHALLENGES VERSUS OPPORTUNITIES

Exploring Lebanon's Unique Challenges

Data governance plays a pivotal role in protecting information, ensuring privacy, and promoting the efficiency of systems across different societies. In Lebanon, a nation marked by a history of disastrous events, data governance faces a series of challenges stemming from governmental, financial, institutional, and community levels. This complex landscape is characterized by a unique assortment of political, cultural, and technological factors, all of which negatively affect the management and protection of vast data in the country (Figure 4).

At the *governmental* arrangement, one of the most pressing challenges is the absence of a comprehensive data governance framework that guides the management, security, and responsible use of data in the country. Hence, data governance is not uniformly present at the national level, resulting in a lack of standardized practices, policies, and procedures for managing data within and across high-level institutions. The

LEBANON'S UNIQUE CHALLENGES



Figure 4: This figure summarizes the unique challenges of Lebanon

sole framework/law addressing some aspects of data governance, including data protection, is Law 81/2018. This law, however, fails to address the evolving data governance landscape. Law 81/2018 gives a lot of privileges to public sector entities by exempting them from certain obligations. This represents a significant deficiency, particularly in times when access to public sector data is crucial for informed decision-making, as entities can feel free to decline collaboration by simply citing 'national security reasons'. De-

spite constant requests to integrate a clause in the law that obliges parliament members to review it twice a year, such a proposal has been consistently rejected. Moreover, political fragmentation, mainly due to sectarianism, and the absence of political will from different parties poses significant hurdles to both the development and proper implementation of comprehensive data governance laws and regulations. To be more specific, the successful implementation of any law requires the establishment of a gov-

erning body that is capable of monitoring the implementation of the law and extending obedience and compliance. However, the nature of the country's political profile complicates the formation of an entity, particularly as the choice of its representatives is purely affected by political interference and sectarianism. This means that decisions can only be made with the approval of all religious parties and the equivalent inclusion of their representatives, even if it means having to choose underqualified individuals for the job description. Furthermore, Lebanon faces a critical issue in terms of cybersecurity, as there is no available cybersecurity law or protocol. A cybersecurity strategy was created as an alternative, with plans for future updates; however, this initiative falls short in safeguarding sensitive data and systems against recurring threats. Furthermore, limited interoperability and multi-sectoral efforts among different state-level data systems and the absence of a unified identifier (ID) for citizens also complicate data governance in the country. Failing to develop a system of unified ID not only results in data fragmentation but also hinders efficient public service delivery. Another barrier to data governance that was specifically evident during COVID-19 was the roles and responsibilities of founding entities. The IMPACT Platform was founded by the central inspection, an entity that oversees the work of all ministries and holds them accountable in the case of any act of misconduct. Despite questions about why this entity was chosen to develop the platform, the main concern was that the central inspection not only founded but also implemented and monitored it, raising governance issues.

At the *financing arrangement*, the public sector's ability to secure salaries for personnel, Information Technology (IT) specialists, cybersecurity experts, and data engineers, and other resources for effective data governance is limited and has been deteriorating due to the multifaceted crisis. Even before the COVID-19 pandemic, the Beirut Blast, and the ongoing economic crisis, funds allocated for data governance were minimal as it was not considered to be a matter of priority. What is more concerning is the fact that ministries are struggling to fill the vacancies left by departing employees, exacerbating the situation even further. When it comes to external funding, Lebanon's history of mismanagement has prevented state-level entities from receiving grants and donations for data governance. Instead, most of these funds are provided to different UN agencies and NGOs, not only resulting in redundant initiatives and poor efficiency but also temporary employment of critical personnel, leading to poor continuity and sustainability of projects.

At the *institutional arrangement*, Lebanon grapples with the fragmentation of data systems across different organizations. Most institutions in the country have adopted various data systems without standardization, making it challenging to efficiently manage, harmonize, and exchange data. For instance, healthcare facilities rely on different electronic medical records (EMR) and health information systems, hindering data sharing and interoperability across institutions. Moreover, the absence or limited number of institutional data management standards and procedures, encompassing data collection, analysis, sharing, storage, and security practices, have led to poor data integrity and reliability. Another issue affecting data management practices at the institutional level is the fact that alignment with recommended global and regional norms, such as HIPAA and GDPR, is completely optional.

At the *community arrangement*, cultural and societal factors have also proven to hinder adequate data governance in Lebanon. Citizen unawareness regarding the importance of data privacy and ownership strongly prevails. This, in turn, fosters a generation of individuals who underestimate the significance and potential risks associated with their data. On the other hand, stakeholders, decision-makers, and other professionals who manage vast quantities of data lack a culture that prioritizes data protection of the population, which further deprives individuals of recognizing their right to adequate data protection and ownership.

Enhancing Health Data Governance in Lebanon for a Brighter Future

In Lebanon, it is evident that the journey towards a data-driven, secure, and efficient future is a challenging endeavor. However, a set of key elements is deemed necessary to facilitate and improve data governance, specifically during health emergencies.

First and foremost, the foundation for successful data governance in Lebanon lies in political will. Without the commitment of government authorities to prioritize data governance, any efforts may remain fragmented and inefficient. A united front from all political factions and governmental bodies is necessary to pave the way for comprehensive data governance initiatives. Data governance is not the responsibility of one specific entity. Multi-sectoral collaboration between and among the public and private sectors is vital for achieving a significant impact. Ultimately, a coordinated approach, involving fundamental stakeholders from various domains, is essential for effective data governance as it brings together diverse perspectives and pro-

A FOUNDATION FOR THE RESPONSIBLE USE OF AI

RESEARCH FINDINGS

LACK OF UNIFIED DATA GOVERNANCE STRUCTURES

Lebanon lacks a national-level, unified data governance framework across institutions.

This fragmented system undermines responsible data use, affecting the healthcare system's efficiency and ability to utilize data for AI-driven solutions.



01

CHALLENGES IN HEALTH DATA SHARING

Data-sharing mechanisms between healthcare institutions are inadequate, creating barriers for leveraging AI in health emergencies.

There is a lack of standardized protocols and interoperability, leading to data redundancy and missed opportunities for analysis.



02

DIGITAL TRANSFORMATION EFFORTS

The Ministry of Public Health (MoPH) initiated efforts like digital health platforms (e.g., cancer patient medication access) and digitizing surveillance systems.

These initiatives provide the groundwork for integrating AI into healthcare, enhancing real-time data collection and decision-making.



03

DATA QUALITY AND SECURITY ISSUES

The absence of data protection laws (e.g., gaps in Law 81/2018) and inconsistencies in data collection across healthcare institutions undermine the quality and security of health data.

Poor data quality poses a challenge for AI adoption, as AI systems require high-quality, standardized data to generate reliable insights.



04

AI TRUST AND ETHICAL CONCERNS

Trust issues regarding data privacy, ethical use, and AI governance remain a concern in Lebanon.

The public is hesitant about sharing sensitive data due to insufficient protections, potentially hindering AI integration.



05

IMPACT ON RESPONSIBLE USE OF AI

ENHANCED DATA ACCURACY

Standardizing health data governance will improve the quality of data used by AI, making AI applications more accurate and reliable in predicting health trends and diagnosing diseases.

IMPROVED RESOURCE ALLOCATION

AI can analyze large datasets for efficient resource management during emergencies, optimizing the distribution of medical staff and supplies.

PREDICTIVE ANALYTICS

AI can be integrated into digital health systems for early detection of outbreaks and health risks, allowing for swift responses in crises like COVID-19 or cholera outbreaks.

TRUST BUILDING

Stronger data governance policies will improve public trust, encouraging more open data sharing, which is crucial for AI-driven healthcare solutions.



motes knowledge sharing, standardization of efforts, and resource pooling, leading to more robust and efficient data governance practices. The need for the adoption of a well-established data governance framework to guide effective data management practices is also evident. Before forging ahead, it is crucial to consider the current profile of data governance in Lebanon. This evaluation will require a detailed assessment of current data collection, analysis, sharing, storage, and security practices on the national level. Understanding the strengths and weaknesses of the existing elements of data governance will be essential for effective improvements.

All the aforementioned features must be supported by the establishment of clear and comprehensive data management and cybersecurity laws and regulations. These legal frameworks will not only protect sensitive data but also ensure that individuals and organizations are held accountable for potential data breaches or misuse, providing a solid foundation for transparency, trust, and accountability. For Lebanon, the way forward in this specific matter is either to amend Law 81/2018 to account for the loopholes regarding data protection and security or to create a new law that specifically addresses the protection of personal data, including health-related data. It is worth noting that a new draft of Law 81/2018 has been developed along with updated implementation decrees; however, this has not been set forth to the parliament due to the current status of political will. Every legislation requires continuous enforcement and regular monitoring. Accordingly, the creation of a well-established regulatory entity that oversees data governance in the country is deemed necessary. This entity should coordinate efforts, perform audits, avoid duplication in initiatives, and consolidate funding from external sources to ensure efficient work and prevent wastage of resources and funds. Those differing perspectives on the composition of this regulatory body, with some suggesting that the committee should be comprised of representatives from various fields.

Another critical opportunity that must be taken into consideration is digitalization, a key enabler of effective data governance. Under this initiative lies the establishment of a unique ID system for citizens to enhance data governance and interoperability between different entities. Adopting a unique ID system will not only streamline data management but also augment public service delivery, as proven by other countries such as Qatar and Kuwait. Increasing the financial means of the public sector is another key element in ensuring sustainable data governance. The allocation of funds for unified national data governance initiatives is more likely to succeed in the long run, ensuring that skilled professionals

are in place to manage and protect data effectively and that necessary resources are available. At the institutional level, the standardization of data governance practices across institutions, including healthcare centers and health-related institutions, is essential to create a coherent and efficient system as it can eliminate confusion and inconsistencies. To make this possible, the MoPH can develop evidence-informed data management guidelines, checklists, or standards that institutions adopt to ensure uniform and effective data governance practices. These guidelines could be incorporated into the accreditation standards for healthcare facilities to monitor their implementation.

Data governance is not solely a technical issue; it is a matter of awareness and advocacy. Data management professionals, healthcare providers, and influential decision-makers must be informed about the importance of data governance, mainly due to the lack of awareness and consistent practices when it comes to data. This can be achieved through lobbying efforts as well as conferences and capacity-building workshops. Moreover, citizens, who often underestimate the significance of data governance and are unaware of their rights to data ownership, must be provided with essential knowledge about their data rights. This can be achieved through mass media campaigns and community involvement activities.

Establishing robust data governance practices is essential for ensuring the equitable and effective provision of healthcare services. Strong data governance lays the foundation for the successful deployment of AI in healthcare. AI technologies depend on high-quality and standardized data to produce accurate insights, enable timely interventions, and enhance decision-making processes, especially in times of health emergencies and outbreaks. Therefore, by fortifying health data governance frameworks, the full potential of AI can be unlocked to enhance healthcare outcomes, mitigate the impact of health crises, and ultimately safeguard public health.

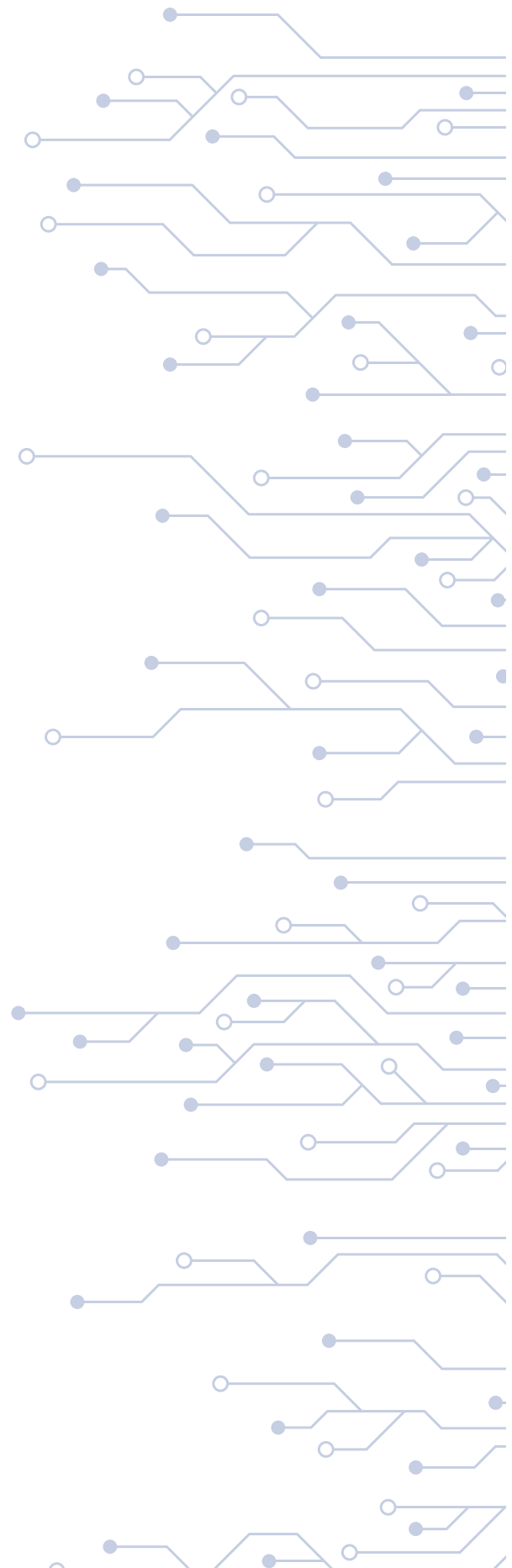
IX. LIMITATIONS

Several limitations were encountered during this study. The sensitive nature of the subject matter under discussion firstly restricted access to information from some institutions, especially military ones. We were unable to thoroughly investigate every facet of health data management due to this restricted access. The inability of several stakeholders to reply to our requests for their participation made it difficult to get their point of view. Notably, we were unable to get

direct feedback from several organizations, including public hospitals and some UN agencies.

X. CONCLUSION

In Lebanon, despite making strides in certain areas, we are still facing inefficiencies. While it is commendable that at an institutional level, there are strong governance practices surrounding health data, these efforts remain fragmented due to the absence of a cohesive national framework governing health data within the country. Moving forward, it is imperative to initiate consultations with key stakeholders to disseminate the findings of this case study. These consultations will be instrumental in charting the necessary steps to enhance health data governance in Lebanon. Establishing a unified and comprehensive national framework for health data governance should be a priority, as it can help bridge the existing gaps and ensure a more effective response to health emergencies while protecting the interests of all stakeholders involved. Guiding the integration of AI technologies through this framework can substantially enhance data analysis capabilities, enabling more precise insights, timely interventions, and informed decision-making processes. The responsible use of AI holds promises to revolutionize healthcare, leveraging extensive datasets to elevate health outcomes, optimize resource allocation, and bolster overall public health preparedness. Yet, it is imperative to underscore that such transformative potential remains unattainable without the steadfast fortification of robust health data governance.



ANNEX 1

Search Strategy for Medline:

1	exp Emergencies/	43191
2	outbreak.mp. or Disease Outbreaks/	144150
3	exp Pandemics/	117421
4	*Epidemics/	10700
5	health emergency.mp.	6360
6	health crisis.mp.	7231
7	crisis.mp.	86802
8	exp COVID-19/ or contingency.mp.	244643
9	Humanitarian n crisis.mp.	493
10	fragile setting.mp.	21
11	polio.mp. or Poliomyelitis/	24815
12	cholera.mp. or Cholera/	29489
13	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12	553824
14	Medical Informatics/ or data governance.mp. or Electronic Health Records/	39010
15	exp security measures/ or exp computer security/	38015
16	contextual integrity.mp.	20
17	personal health information.mp. or Health Records, Personal/	2271
18	organizational forms.mp.	266
19	information management/ or data collection/ or data management/ or health information management/ or health information exchange/	99411
20	information governance.mp.	248
21	data governance.mp.	393
22	data stewardship.mp. or Access to Information/	7152
23	data privacy.mp.	1332
24	informed consent.mp. or Informed Consent/	72397
25	“information storage and retrieval”/ or health information interoperability/	21805
26	data storage.mp.	4705
27	data architecture.mp.	81
28	data collection.mp. or Data Collection/	188417
29	data quality.mp. or Data Accuracy/	13974
30	data lifecycle.mp.	37
31	compliance.mp.	190606
32	artificial intelligence.mp. or Artificial Intelligence/	59372
33	cybersecurity.mp.	977
34	regulations.mp.	57956
35	guidelines.mp. or exp Guideline/ or Guideline Adherence/	563178
36	data processing.mp.	27217
37	data breaches.mp.	155
38	14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37	1204252
39	Lebanon.mp. or Lebanon/	7947
40	13 and 38 and 39	49

Search Strategy for PubMed:

((("Emergencies"[MeSH Terms] OR "Disease Outbreaks"[MeSH Terms] OR "Emergency Medical Services"[MeSH Terms] OR "COVID-19"[MeSH Terms] OR "Poliomyelitis"[MeSH Terms] OR "Cholera"[MeSH Terms]) AND "Medical Informatics"[MeSH Terms]) OR "Data Management"[MeSH Terms] OR "Security Measures"[MeSH Terms] OR "Artificial Intelligence"[MeSH Terms] OR "Guidelines as Topic"[MeSH Terms]) AND "Lebanon"[MeSH Terms])

Search Strategy for Google:

(emergen*|"disease outbreaks"|pandemics|epidemics|"health emergency"|"health crisis"|COVID-19|polio|poliomyelitis|cholera) ("medical informatics"|"data governance"|"health records"|"information management"|"data collection"|"data stewardship"|"data access"|"data privacy"|"data storage"|"data architecture"|"data quality"|"data accuracy"|"data lifecycle"|"computer security"|cybersecurity|"data processing"|"data breaches"|guidelines|compliance) (Lebanon)

ANNEX 2

HEALTHCARE DATA GOVERNANCE IN LEBANON: CHALLENGES AND OPPORTUNITIES

Preamble

Thank you for taking the time for this meeting. Your participation is highly appreciated.

We are pleased to invite you to participate in this interview as part of a regional study on health data governance. In this meeting, we will examine your experience with health data governance before, during, and after health emergencies in Lebanon. More specifically, we will explore the components of the health data cycle, which include data planning, collection, analysis, storage, sharing, usage, lessons learned, and the challenges in health data governance. Your input is highly valuable and will help in supporting and strengthening health data governance and the responsible use of emerging technologies in Lebanon. The interview guide is divided into four sections on health data governance. The meeting will take up to 45-60 minutes of your time.

During the interview, we would like to record the discussion (and/or [name of notetaker] will be taking notes) to ensure we adequately capture your ideas during the conversation. However, the responses will remain confidential and your name will not be attached to any comments you make. If you prefer not to record, we will take only notes from the interview. Do you have any questions before we begin?

INTRODUCTORY QUESTION

Relevant Institutes:

Health Delivery Institutions

- 1) Can you please provide an overview of the health data management system in health emergencies in your institution?**

Relevant Institutes:

Data Experts

- 2) How did the health emergencies in the country such as Polio, COVID-19, and Cholera, impact your data management systems?**

SECTION 1: DATA MANAGEMENT

Relevant Institutes:

All Stakeholders

- 1) Do current health data governance policies clearly define the roles and responsibilities within the data architecture in health emergencies?**

Probes:

- a. *E.g., the data rights and ownership are codified in legislations, laws, policies, and regulations*
- b. *To what extent are your data rights and ownership policies aligned with regional and global norms?*

2) How do you ensure that the health data-related rights i.e., the right to control the use of data, the right to decline participation in data collection, the right to withdraw data from a system, and the right to obtain benefit from shared data, are protected?

3) How do you ensure that the health data provided is owned by individuals and communities that provide it in health emergencies

4) What are potential facilitators that could enhance the community's trust and ownership of health data?

Probes:

- a. *The establishment of institutions that would define rules of data collection, processing, storage, analysis, use, sharing, and disposal in a manner that respects the data rights and ownership of individuals and communities, while also actively providing them the means to exercise their data rights and ownership*
- b. *community engagement in developing data governance mechanisms including data management, and decision-making related to the collection and usage of health data in health emergencies.*

5) Have there been any differences in data management, rights, and ownership processes before the COVID-19 pandemic, during and after the pandemic?

SECTION 2: DATA COLLECTION AND QUALITY

Relevant Institutes:

All Stakeholders

1) Could you please provide us with an overview of the data collection processes in your institution in health emergencies?

Probes:

- a. *What policies and procedures guide the data collection process during Polio, COVID-19, and Cholera?*
- b. *What type of data do you collect from individuals at your institution during health emergencies?*
- c. *What data collection tools are used in your institution?*
- d. *Do the data collection methodologies and processes ensure the inclusiveness of all groups and populations? (e.g., age, sex, gender identity, race, ethnicity, citizenship status, refugee status, sexual identity, ability) or economic characteristics (e.g., education level, income status, profession).*

2) How do you identify potential risks that an individual might face during the collection and usage of data? (e.g., moderate risks such as loss of data privacy to severe as risks to personal safety, risks of insufficient or incorrect care, exploitation)

Probes:

- a. *In the event of risks, what are the risk mitigation policies adopted by your institution to reduce individual and collective risks?*
- b. *What are the procedures to address incidences of unlawful, inappropriate, and unethical collection or use of health data?*

3) How is consent attained from individuals during data collection in health emergencies?**Probes:**

- a. *Is the defined purpose behind collecting the data communicated with individuals?*
- b. *Can you describe a situation where you might not obtain the consent of an individual?*

4) Can you briefly describe how you ensure the quality of the collected data during health emergencies?**Probes:**

- a. *What are the protocols that guide the quality of data in your institutions during health emergencies?*
- b. *How do evidence and best practices inform your data quality practices?*
- c. *What efforts are being made to strengthen the capacity of health workers in data use and collection during health emergencies?*

5) Have there been any differences in data collection and data quality processes before the COVID-19 pandemic, during and after the pandemic?**SECTION 3: DATA ANALYSIS****Relevant Institutes:**

All Stakeholders

1) How was the data collected used to inform decision-making during health emergencies?**Probes:**

- a. *e.g., improved access to health services, robust surveillance, better diagnostics and predictive analysis, precision medicine*
- b. *How does the health data collected contribute to improving the operational components of the health system (e.g., supply chain, health workforce management)?*
- c. *Did the informed decisions take into consideration the needs of marginalized groups such as refugees, and people with disabilities...?*

2) Have there been any differences in data analysis processes before the COVID-19 pandemic, during and after the pandemic?

SECTION 4: DATA STORAGE

Relevant Institutes:

All Stakeholders

- 1) Could you please briefly describe your data storage architecture for data related to polio, COVID, and Cholera?

Probes:

- a. Where is the data stored (e.g., cloud servers or onsite servers, etc)?
- b. How long is data stored? Please describe your guidelines on a timeframe after which data should be deleted or otherwise removed from the system
- c. How is the data security maintained during data storage (e.g., encryption)?

- 2) Have there been any differences in data storage before the COVID-19 pandemic, during and after the pandemic?

SECTION 5: DATA SECURITY

Relevant Institutes:

All Stakeholders

- 1) What are the current health data protection policies or laws that you abide by during health emergencies?

Probe:

- a. The General Data Protection Regulation (GDPR) or the Personal Data Protection Act (PDPA) of the Protection of Personal Information Act (POPI Act), etc.

- 2) Is the data anonymized and/or encrypted to keep individuals' privacy? Can individuals' details be viewed or recognized?

Probe:

- a. The General Data Protection Regulation (GDPR) or the Personal Data Protection Act (PDPA) of the Protection of Personal Information Act (POPI Act), etc....

- 3) In the event of data security threats, what are the processes to mitigate such risks?

Probes:

- a. This may include using unique identifiers in place of an individual's name; placing limits on how long data may be stored; adding enhanced security measures for personally identifiable or otherwise sensitive data; reassurance initiatives on cybersecurity; safe storage guidelines for confidential data; and efforts to respect, protect and uphold the right to privacy as a system design principle.
- b. How are affected individuals and communities informed in the event of data breaches?

4) How is data security ensured during health emergencies?**Probe:**

- a. *What are some of the lessons learned from COVID-19?*

5) Have there been any differences in data security processes before the COVID-19 pandemic, during and after the pandemic?**SECTION 6: DATA SHARING AND INTEROPERABILITY****Relevant Institutes:**

All Stakeholders

1) Could you briefly describe the current data-sharing mechanisms which promote the interoperability of data systems across different institutions in health emergencies?**Probe:**

- a. *Are there any policies, protocols, frameworks, or guidelines that guide data-sharing processes across institutions, agencies, and sectors?*

2) What are the potential gaps in current data structures which may hinder data sharing in health emergencies?**Probe:**

- a. *infrastructure, policies, human workforce capacity, etc....*

3) What are the current opportunities that can be leveraged to improve data sharing in health emergencies?**SECTION 7: DATA MONITORING, & EVALUATION****1) Can you briefly describe your data monitoring and evaluation processes during health emergencies?****Probes:**

- a. *How often do you conduct evaluations of your practices?*
- b. *What mechanisms through which individuals and communities can report data misuse, make inquiries into health data structures and processes, remove their data from a system, and provide general feedback are used?*
- c. *How are accountability mechanisms communicated with individuals and communities?*

2) Have there been any differences in data M&E processes before the COVID-19 pandemic, during and after the pandemic?

SECTION 8: LESSONS LEARNED AND NEXT STEPS

Relevant Institutes:

Hospitals, Primary Healthcare Centers, Private Insurance Companies, Ministry of Public Health, & Labs

- 1) **How do you make sure that health data governance policies are respected when adopting new technology in your institution? (i.e., emerging artificial intelligence and machine learning)**
- 2) **What are the potential challenges that may be faced in the use of emerging technologies such as artificial intelligence?**
- 3) **Are there any specific challenges with data governance during emergencies in Lebanon?**
- 4) **What are the key next steps to improve data governance in Lebanon during health emergencies?**

ANNEX 3:

LEBANON CASE STUDY- LEBANON FIELD QUESTIONS VERSUS HEALTH DATA PRINCIPLES FRAMEWORK

DATA MANAGEMENT			
Health Data Governance Principles by World Bank 2022		Question in English	
Overview questions		Can you please provide an overview of the health data management system in health emergencies in your institution?	
		How did the health emergencies in the country such as Polio, COVID-19, and Cholera, impact your data management systems?	
		Are there any specific challenges with data governance during emergencies in Lebanon?	
		What are the key next steps to improve data governance in Lebanon during health emergencies?	
P.3. Prioritize Equity	P.3.2 Establish Data Rights & Ownerships	Define clear governance roles and responsibilities	Do current health data governance policies clearly define the roles and responsibilities within the data architecture in health emergencies?
			i.e., the roles of the data owner, data custodian, data processor, data steward, data trustee, and data use beneficiary?
			Who owns health data during health emergencies?
			Who has access to health data during health emergencies?
	Codify data rights and ownership	How do you ensure that the health data-related rights i.e., the right to control the use of data, the right to decline participation in data collection, the right to withdraw data from a system, and the right to obtain benefit from shared data, are protected?	
		How do you ensure that the health data provided is owned by individuals and communities that provide it in health emergencies?	
		E.g., the data rights and ownership are codified in legislations, laws, policies, and regulations	
		To what extent are your data rights and ownership policies aligned with regional and global norms?	
		Have there been any differences in data management, rights, and ownership processes before the COVID-19 pandemic, during and after the pandemic?	
		What are potential facilitators that could enhance the community's trust and ownership of health data?	
Develop health data trusts and health data cooperatives			

			<p>The establishment of institutions that would define rules of data collection, processing, storage, analysis, use, sharing, and disposal in a manner that respects the data rights and ownership of individuals and communities, while also actively providing them the means to exercise their data rights and ownership</p> <p>Community engagement in developing data governance mechanisms including data management, and decision-making related to the collection and usage of health data in health emergencies</p>
DATA COLLECTION			
Health Data Governance Principles by World Bank 2022			Question in English
P.1. Protect People	P.1.1 Protect Individuals & Communities	Address individual and collective risk	How do you identify potential risks that an individual might face during the collection and usage of data? (e.g., moderate risks such as loss of data privacy to severe as risks to personal safety, risks of insufficient or incorrect care, exploitation)
			In the event of risks, what are the risk mitigation policies adopted by your institution to reduce individual and collective risks?
		Collect data with a defined purpose	Could you please provide us with an overview of the data collection processes in your institution in health emergencies?
			What policies and procedures guide the data collection process during Polio, Covid, and Cholera?
			What type of data do you collect from individuals at your institution during health emergencies?
	Have there been any differences in data collection and data quality processes before the COVID-19 pandemic, during and after the pandemic?		
	Use secure data collection and storage mechanisms	What data collection tools are used in your institution?	
	Provide guidance specific to marginalized groups and populations	Do the data collection methodologies and processes ensure the inclusiveness of all groups and populations? (e.g., age, sex, gender identity, race, ethnicity, citizenship status, refugee status, sexual identity, ability) or economic characteristics (e.g., education level, income status, profession).	
	P.1.2. Build trust in data systems	Ensure consent is informed and understood in all its complexities	How do you take patients' consent when collecting personal health data (e.g in written forms, verbal, etc.)?
			How is consent attained from individuals during data collection in health emergencies?

			Is the defined purpose behind collecting the data communicated with individuals? Can you describe a situation where you might not obtain the consent of an individual?		
		Obtain collective consent where appropriate	How do you ensure high data quality? Do you encounter a lot of errors in data entry (e.g. entering data into wrong fields, or entering wrong numbers)? How do you remedy that?		
		Ensure data quality, availability, and accessibility	Can you briefly describe how you ensure the quality of the collected data during health emergencies? What are the protocols that guide the quality of data in your institutions during health emergencies?		
		Reinforce health data governance with evidence	How do evidence and best practices inform your data quality practices?		
		Institute feedback and accountability mechanisms	What are the procedures to address incidences of unlawful, inappropriate, and unethical collection or use of health data?		
		P.2. Promote Health Value	P.2.1 Enhance Health Systems Services	Enable and empower frontline health workers	What efforts are being done to strengthen the capacity of health workers in data use and collection during health emergencies?
		DATA ANALYSIS			
Health Data Governance Principles by World Bank 2022			Question in English		
P.2. Promote Health Value	P.2.1 Enhance Health Systems and Services	Evaluate the benefits of health data	How was the data collected used to inform decision-making during health emergencies? Have there been any differences in data analysis processes before the COVID-19 pandemic, during and after the pandemic?		
		Use data to enhance health services for individuals and communities	e.g., improved access to health services, robust surveillance, better diagnostics and predictive analysis, precision medicine		
		Address health system efficiency, effectiveness and resilience	How does the health data collected contribute to improving the operational components of the health system (e.g., supply chain, health workforce management)?		
P.3. Prioritize Equity	P.3.1 Promote Equitable Benefits from Health Data	Promote equitable impact and benefit	Did the informed decisions take into consideration the needs of marginalized groups such as refugees, and people with disabilities...?		

DATA STORAGE			
Health Data Governance Principles by World Bank 2022			Question in English
P.1. Protect People	P.1.4. Protect Individuals and Communities	Use secure data collection and storage mechanisms	Could you please briefly describe your data storage architecture for data related to polio, COVID, and Cholera?
			Where is the data stored (e.g., cloud servers or onsite servers, etc)?
			How long is data stored? Please describe your guidelines on a timeframe after which data should be deleted or otherwise removed for the system
			Have there been any differences in data storage before the COVID-19 pandemic, during and after the pandemic?
	P.1.3 Ensure Data Security	Require strong technical security measures for data processing	How is the data security maintained during data storage (e.g., encryption)?
DATA SECURITY			
Health Data Governance Principles by World Bank 2022			Question in English
P.1. Protect People	P.1.1 Protect Individuals & Communities	Use de-identification and anonymization	Is the data anonymized and / or encrypted to keep individuals' privacy? Can individuals' details be viewed or recognized?
			Who has access to the data in health emergencies?
	P.1.3 Ensure Data Security	Require strong technical security measures for data processing	How is data security ensured during health emergencies?
			What are some of the lessons learned from COVID-19?
			In the event of data security threats, what are the processes to mitigate such risks?
			This may include using unique identifiers in place of an individual's name; placing limits on how long data may be stored; adding enhanced security measures for personally identifiable or otherwise sensitive data; reassurance initiatives on cybersecurity; safe storage guidelines for confidential data; and efforts to respect, protect and uphold the right to privacy as a system design principle.
		Ensure transparency around data breaches	How are affected individuals and communities informed in the event of data breaches?

		Consider federated data systems	Have there been any differences in data security processes before the COVID-19 pandemic, during and after the pandemic?
DATA SHARING AND INTEROPERABILITY			
Health Data Governance Principles by World Bank 2022			Question in English
P.2. Promote Health Value	P.2.2. Promote data sharing and interoperability	Establish Data Sharing rules and guidelines	Could you briefly describe the current data-sharing mechanisms which promote the interoperability of data systems across different institutions in health emergencies?
			Are there any policies, protocols, frameworks, or guidelines that guide data-sharing processes across institutions, agencies, and sectors?
		Promote interoperability of data systems	What are the potential gaps in current data structures which may hinder data sharing in health emergencies?
			infrastructure, policies, human workforce capacity, etc..
	Support multi-sector partnerships	What are the current opportunities that can be leveraged to improve data sharing in health emergencies?	
DATA MONITORING AND EVALUATION			
Health Data Governance Principles by World Bank 2022			Question in English
P.1. Protect People	P.1.2 Build Trust in Data Systems	Establish transparent and accessible processes and systems	Can you briefly describe your data monitoring and evaluation processes during health emergencies?
			How often do you conduct evaluations of your practices?
			What mechanisms through which individuals and communities can report data misuse, make inquiries into health data structures and processes, remove their data from a system, and provide general feedback are used?
		Institute feedback and accountability mechanisms	How are accountability mechanisms communicated with individuals and communities?
AI AND TECHNOLOGIES			
Health Data Governance Principles by World Bank 2022			Question in English
P.2. Promote Health Value	P.2.3 Facilitate innovation using health data	Apply health data governance to emerging technologies	How do you make sure that health data governance policies are respected when adopting new technology in your institution? (i.e., emerging artificial intelligence and machine learning)
			What are the potential challenges that may be faced in the use of emerging technologies such as artificial intelligence?



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