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

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Governance of Women's Health Data in Palestine: A Case Study

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GOVERNANCE OF WOMEN'S HEALTH DATA IN PALESTINE

Case Study

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ABSTRACT

The growing global trend that has seen the healthcare sector adopt digital technologies, specifically artificial intelligence (AI), for a variety of purposes is also taking root in Palestine. With the introduction of these technologies, there is a pressing need to examine the policies and practices governing their use. This study views the issue of governance of healthcare data in Palestine through the prism of women's health data. The purpose of this research is to assess the awareness of different stakeholders of health-data governance and to understand existing practices or frameworks in this domain. This research was conducted in accordance with the principles that the World Bank has developed and proposed to guide the governance of health data across public-health systems and policies. The study employed a qualitative approach, involving in-depth semi-structured interviews with stakeholders working with women's health data at different levels and across different healthcare providers within the Occupied West Bank. The study then synthesized the evidence collected into policy recommendations, which entail an imperative to 1) advocate for the development and implementation of national policies and a regulatory framework for handling health data, 2) develop information-technology infrastructure in all health facilities, including women's healthcare clinics, 3) promote participatory approaches and data sharing among different healthcare sectors, and 4) propose capacity building programs.

I. INTRODUCTION

Globally, there has been a growing trend toward adopting digital technologies, including artificial intelligence (AI), in the healthcare sector.[1] These digital health interventions have, in some instances, enhanced the use and accessibility of healthcare services and fostered better coordination among healthcare providers.[2] Digital health interventions have expanded healthcare coverage and overcome geographical, social, and behavioral barriers to healthcare services provision, a fact that highlights their potential to improve service delivery.[3] These interventions have been important in transforming the delivery of health services, including improved diagnostics and personalized medicine, enhanced efficiency, and data-driven predictive analysis. [4]

Enhancing the equitable provision of healthcare services is attainable through data-driven, AI and digital health systems, which offer an opportunity to progress toward establishing sustainable and resilient public health systems capable of providing universal health coverage (UHC).[5] The recent exponential increase in health data utilization due to the COVID-19 pandemic has raised concerns about the presence, or lack thereof, of adequate legal and regulatory data governance safeguards, both at the policy and operational levels, particularly in resource-constrained and fragile contexts like Palestine.[6]

The adoption of digital health interventions is beginning to take root in Palestine. A 2023 research project, conducted in Palestine and Jordan, focused on identifying and mapping digital health initiatives related to reproductive, maternal, newborn, and child health (RMNCH).[7] Assessing the maturity level of these initiatives in terms of implementation and evaluation,[8] the research showed that the approaches to data governance lagged behind those related to IT infrastructure. Moreover, several stakeholders who were interviewed for that research lacked sufficient awareness of the importance of data governance as part of a health information system.

The aforementioned findings point to a pressing need to examine the governance landscape in Palestine among various stakeholders, with a focus on women's health data. This research therefore aims to conduct a systematic assessment of stakeholders' awareness of health data governance and understand existing practices and frameworks, focusing on women's health data governance in particular while looking at health data more broadly. The study includes stakeholders at different levels of involvement:

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[1] World Health Organization, "eHealth and innovation in women's and children's health: a baseline review: Based on the Findings of the 2013 Survey of CoIA Countries by the WHO Global Observatory for eHealth." March 2014. https://iris.who.int/handle/10665/111922.

[2] Labrique, Alain, et al. "Best Practices in Scaling Digital Health in Low and Middle Income Countries." *Globalization and Health* 14, no. 1 (2018): 1–8. https://globalizationandhealth.biomedcentral.com/articles/10.1186/s12992-018-0424-z.

[3] Labrique, Alain, et al. "Best Practices in Scaling Digital Health in Low and Middle Income Countries." *Globalization and Health* 14, no. 1 (2018): S5–S17. https://globalizationandhealth.biomedcentral.com/articles/10.1186/s12992-018-0424-z.

[4] Bharati, Subrato, et al. "A Review on Explainable Artificial Intelligence for Healthcare: Why, How, and When?" *IEEE Transactions on Artificial Intelligence* 5, no. 4 (2012). https://ieeexplore.ieee.org/document/10101766.

[5] Olu, Olushayo, et al. "How Can Digital Health Technologies Contribute to Sustainable Attainment of Universal Health Coverage in Africa? A Perspective." *Frontiers in public health* 7, no. 341 (2019). https://pubmed.ncbi.nlm.nih.gov/31803706/

[6] Tiffin, Nicki, et al. "How to use relevant data for maximal benefit with minimal risk: digital health data governance to protect vulnerable populations in low-income and middle-income countries." *BMJ Global Health* 4, no. 2 (2019). https://gh.bmj.com/content/4/2/e001395.info

[7] Nemer, Maysaa, et al. "Personal data governance and privacy in digital reproductive, maternal, newborn, and child health initiatives in Palestine and Jordan: a mapping exercise." *Frontiers in Digital Health* 5 (2023). https://www.frontiersin.org/journals/digital-health/articles/10.3389/fdgth.2023.1165692/full

[8] Alyahya, Mohammad S., et al., "Maturity Level of Digital Reproductive, Maternal, Newborn, and Child Health Initiatives in Jordan and Palestine." *Methods of Information in Medicine* 61, no. 05/06 (2022): 139-154. https://pubmed.ncbi.nlm.nih.gov/36379469/

policy makers, mid-level managers, healthcare providers, and beneficiaries. The objectives are: 1) to gain insights into the existing practices and frameworks in health data governance and the state of the regulatory landscape across different levels (see methodology section), with an emphasis on women's health data; 2) to evaluate awareness and knowledge of health data governance among stakeholders at various levels within the health system, with a specific focus on women's health data; and 3) to identify gaps and offer policy recommendations for responsible data governance in the Palestinian health sector.

To achieve the objectives, our research was conducted in accordance with the World Bank's Health Data Governance Principles, authored by and intended as a guide to be utilized across public health systems and policies.[9] These principles are designed to inform and reinforce health-data governance models, instruments, treaties, regulations, and standards worldwide. They are regarded as a tool to promote the use of digital technologies and data for the benefit of collective health and well-being. The principles encompass three interconnected objectives: (1) protect people — as individuals, as groups, and as communities; (2) promote health value — through data sharing and innovative uses of data; and (3) prioritize equity — by ensuring equitable distribution of benefits derived from the use of data in healthcare systems.[11]

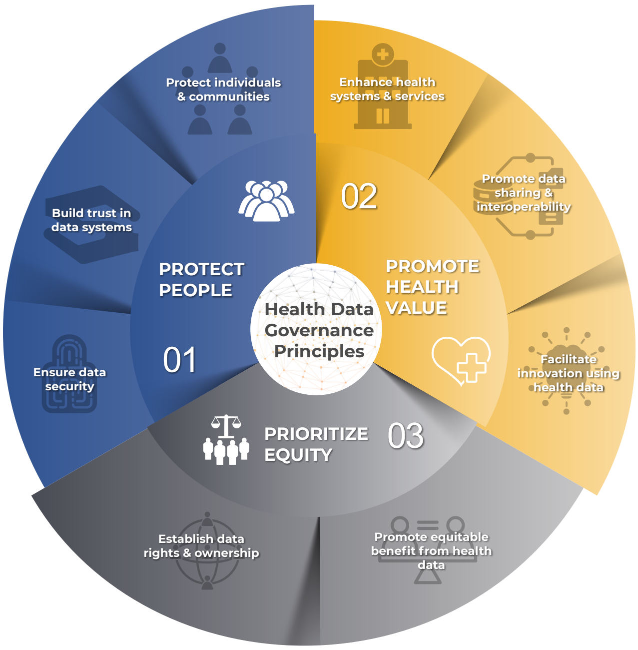

Figure 1: The Health Data Governance Principles framework.[10]

II. BACKGROUND RESEARCH

Women's Health and Data in Palestine

Healthcare services in Palestine are provided by four main entities: the Ministry of Health, the United Nations Relief and Works Agency for Palestine Refugees (UNRWA), non-governmental organizations (NGOs), and the private sector. Ministry of Health facilities[12,13] and UNRWA clinics[13] provide reproductive healthcare services including antenatal, perinatal, and postnatal services, high-risk-pregnancy care, family planning and other women's healthcare services.

Based on the latest annual health report by the Palestinian Ministry of Health in 2023, women constitute 49.2 percent of the Palestinian population. Of these women, 50 percent are in their reproductive years, aged between 15 and 49 years. The report noted that 94,500 pregnant women were registered either at Ministry of Health or UNRWA primary healthcare clinics in 2022. The report estimated that each woman visited the clinic around 4.3 times during pregnancy, with women in Gaza making more visits on average than women in the West Bank.[14] This average is half the recommended frequency of visits for optimum mother and child health, according to the WHO.[15] In a 2022 report, the Palestinian Central Bureau of Statistics (PCBS) estimated that around 94.8 percent of pregnant women visited primary healthcare clinics at least four times during their pregnancy in 2020.[16] Cesarean section deliveries increased from 15 percent in 2006[17] to 28.2 percent in the West Bank

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[9] Under the guidance of the Transform Health Coalition, health data governance principles were developed by a diverse group of global and regional experts in digital health and data governance. This effort included the participation of 200 digital health specialists from 130 organizations worldwide, encompassing governments, international organizations, civil society, academic institutions, and the private sector. These principles aim to guide the use of data in health systems.

[10] The World Bank's Health Data Governance Principles (https://healthdatagovernance.org/principles/), revisualised

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[11] Transform Health, "Health Data Governance Principles: Universalising the benefits of health digitalisation," 2022. https://healthdataprinciples.org/principles

[12] Palestinian Ministry of Health, General Administration for Healthcare. https://site.moh.ps/Index/Circle/CircleId/15/Language/ar

[13] UNRWA. "What we do: Services." https://www.unrwa.org/what-we-do/services.

[14] Palestinian Ministry of Health, "Health Annual Report Palestine 2022." Palestinian Health Information Center (PHIC) (2023). https://site.moh.ps/Content/Books/7B3a7X1pBCWOEINRCY7q9EWTDQUqfaw9pPoeWDZ6OsSLnxZqVGBuyY_rDZGco6Zb5437Fqi2OJDNvtmezzUdHQ79UmhKgrDjxmrzxFxoI5Zeu.pdf

[15] World Health Organization, "WHO recommendations on antenatal care for a positive pregnancy experience." (2016). https://www.who.int/publications/i/item/9789241549912

[16] Palestinian Central Bureau of Statistics. "Women and men in Palestine: Issues and statistics." (2022). https://www.pcbs.gov.ps/Downloads/book2621.pdf

[17] Palestinian Central Bureau of Statistics. "Palestinian Family Health Survey, 2006: Preliminary Report." https://www.pcbs.gov.ps/Portals/_pcbs/PressRelease/English_Report.pdf

and 22.4 percent in Gaza in 2020. The Palestinian Ministry of Health has expressed concern about this rise and attributed it primarily to procedures conducted in private clinics, emphasizing the need for strict regulations to prevent further increases. The maternal mortality ratio decreased from 38 in 2009 to 13.8 per 100,00 live births in 2016.[18]

In 2011, the Women's Affairs Ministry issued a strategic plan to provide a regulatory framework "for combating violence against women and upholding their rights."[19] Improving reproductive health indicators and supporting the development and sustainability of the reproductive health sector are major expected outcomes in the National Health Strategy proposed by the Ministry of Health, (2017).[20] This was planned to be achieved through providing comprehensive healthcare services, promoting health programs and introducing a family health approach. The priorities are targeted toward enforcing efforts for continuity in encouraging breastfeeding and providing for the needs and equipment for family planning. The national strategy for reproductive and sexual health in Palestine has three main goals: to ensure the availability and accessibility of high-quality reproductive healthcare services in all clinics, promote the level of community awareness, and enhance the sustainability and governance of the reproductive health sector.[21] Strengthening and enhancing services targeting reproductive health and women's health on the information-technology level is being addressed through plans to integrate the computerized systems among facilities and sectors (Ministry of Health and UNRWA).

Digital technology and healthcare in Palestine: the situation and available regulations

While there are some policies and regulatory frameworks that address digital technology in the Palestinian healthcare sector, legislation concerning the use of AI is lacking. The introduction of computers into the Palestinian healthcare system began in 2007 in Ministry of Health facilities. Since then, the information-technology infrastructure in the public sector has been bolstered. For instance, by 2017, eight hospitals had computerized services, and the Ministry of Health continues to integrate electronic systems in health facilities, especially in mother and child health clinics.[20,22] However, the healthcare system struggles with infrastructure deficiencies and a reliance on funder and donor agendas, in addition to a lack of training programs, data documentation, regulatory frameworks, and policies.[23] Thus, strengthening governance is a main goal for the Ministry of Health, according to its 2021 strategic health sector plan.

This report reveals the challenges facing the healthcare system, which include the lack of management qualifications and skills, over-centralization and insufficient independence among mid-level managers, and uncertainty as to how regulatory strategic plans are to be employed and implemented. These issues are addressed through structural reviews of healthcare organizations and efforts to introduce regulations to enhance work quality.

Improving information-technology infrastructure, services, and equipment and enhancing health governance, collaboration, and integration among health sectors are two of the National Health Strategy objectives. Another strategic objective is to keep up with technological advancements by providing continuous training and education for personnel. This objective aligns with the regulation issued in the Council of Ministers' Decision 6/2020 on the Principles of Information Security Management,[24] which mandates that organizations include the roles and responsibilities related to information security as part of their employment structures, in addition to training employees and raising their proficiency and qualifications in this field. The directive also obliges employees to maintain information confidentiality. Crimes committed using digital technology are addressed in the law by Decree 10/2018 on cybercrime,[25] which sets the consequent penalties for violating the regulations.

Advocating for raising awareness among Palestinians of their digital rights, the Arab Center for

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[18] Palestinian Ministry of Health's General Administration for Women's Health and Development. "National Strategy for Reproductive and Sexual Health in Palestine 2018-2022." https://site.moh.ps/Content/Books/kPjNja4GhFYwgaY98s9rQBen7Vnn2poe4yWGVPhTEZ8Nu6SrPY4DED_njgr6oa3k6xFltgtsjvOtOVjxEvwzepckDDJVJy7aPUHy2z6eUTWoQ.pdf

[19] Palestinian Women's Affairs Ministry. "National Strategy for combatting violence against women 2011-2019." https://www.efi-rcso.org/sites/default/files/2021-03/palestinian%20authority%20national%20strategy%20to%20combat%20VAW%202011-2019%20-EN.pdf

[20] Palestinian Ministry of Health. "*National Health Strategy 2017–2022.*" General Directorate of Health Policies and Planning. (2017). https://site.moh.ps/Content/Books/OhV2yDbK3NBuMaBgzXrM13Tgf5Ek46VMsINeNQ9CvdRJ68xSlueheN_CUmin4TqPtVNgd7v3aBpOzbD57AZWl5OPlGu6RsGzmnu3mNE745Rr5.pdf

[21] Palestinian Ministry of Health's General Administration for Women's Health and Development. "National Strategy for Reproductive and Sexual Health in Palestine 2018-2022." https://site.moh.ps/Content/Books/kPjNja4GhFYwgaY98s9rQBen7Vnn2poe4yWGVPhTEZ8Nu6SrPY4DED_njgr6oa3k6xFltgtsjvOtOVjxEvwzepckDDJVJy7aPUHy2z6eUTWoQ.pdf

[22] Palestinian Ministry of Health. *Health Sector Strategic Plan: Southern Governorates 2021–2025* (2021)https://www.moh.gov.ps/mohStatL/E_Strategic_Plan_2021-2025.pdf

[23] Palestinian Ministry of Health. *Strategic Plan for Health Information Management 2023–2025: For the Health Sector in the Southern Governorates*. (2023). https://www.moh.gov.ps/mohStatL/HIM-Strategic-Plan.pdf

[24] Cabinet Resolution 6/2020, Principle of information security management, http://muqtafi.birzeit.edu/Legislation/GetLegFT.aspx?lnk=2&LegPath=2020&MID=17425

[25] Decree Law 10/2018 regarding cybercrimes, http://muqtafi.birzeit.edu/pg/getleg.asp?id=17018

the Advancement of Social Media issued a document in 2020, based on the United Nations Human Rights Council, with "The Right to Privacy & Data Protection" as one its main pillars.[26]

III. METHODOLOGY

Theoretical Framework: World Bank's Health Data Governance Principles

The study design is guided by the World Bank's proposed principles, which are meant to foster sound health-data governance in promotion of human rights and equity in a resilient healthcare system.

The first principle addresses the protection of individuals and communities from data violations and promotes the value of data utilization for health purposes and the application of evolving data-security practices.

The second principle states that governance should effectively promote data sharing and enable innovative use of data, which would promote health value.

The last principle is to prioritize equity, namely by ensuring that individuals and communities are equitably represented in health data and the benefits gained from the sharing and utilization of data.

Two interview guides were developed to question healthcare providers and policymakers based on this theoretical framework.

Study Design

A qualitative approach was utilized using in-depth semi-structured interviews with stakeholders working on women's health data at different levels and across different healthcare providers within the West Bank, Palestine. We utilized purposive and snowballing sampling techniques to identify and select key interviewees among stakeholders, making sure to represent different healthcare settings (hospitals, primary healthcare clinics, labs, pharmacies, and health insurance companies); different types of providers (governmental, private, and NGOs); and varying stakeholders (upper management and policy makers; healthcare providers including physicians, nurses, midwives, and lab technicians; health insurance employees; and administrative employees). Data was collected between June and August 2023, and most interviews were held at the stakeholders' workplaces, except for two, which were conducted online. Most interviews were audio recorded with the participants' consent, but four stakeholders refused to have the interview recorded. Thus, notes were taken during the interviews. A total of 20 interviews were conducted.

Stakeholder Interviews

The interview guide (Appendix A) has two main sections: (1) awareness of data governance and its importance and (2) existing practices or frameworks related to health data governance in the Palestinian health sector. Questions for each section were developed in accordance with the theoretical framework proposed by the World Bank and through consultations with experts in the field. In order to capture relevant information from different stakeholders, two sets of interview questions were developed: one for healthcare professionals and another for policymakers, administrators, and insurance personnel.

Ethical Considerations

The study proposal and interview guide were approved by the ethics review committee at the Institute of Community and Public Health in Birzeit University — Ref-No. 2023 (4 – 1). Oral informed consent was obtained from all participants after the study's aims and procedures were explained to them. Participants were informed that the data would be handled confidentially, that only the research team would have access to it, and that no names or identifying information would be published. They were also informed that their participation was voluntary and that they could refrain from answering any question or halt their participation at any point with no consequences.

IV. FIELDWORK FINDINGS

Awareness and knowledge of stakeholders about Data Governance

Most healthcare providers are not familiar with data governance in healthcare, its pillars, importance, and goals. However, in their responses, they affirm the importance of certain elements related to health data:

1) Privacy and security: Data should be accessed only by health workers in the facility and should not be shared with any entity without patient approval.

2) Quality and accuracy: Data entry should be complete and honest.

3) Storage: Data should be retrieved for patients at every visit.

4) Monitoring: Audits should be conducted to avoid/correct mistakes.

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[26] 7amleh–The Arab Center for Social Media Advancement. "Know your digital rights." https://7amleh.org/

The policymakers' perspectives on data governance principles focus on the need for high-quality, reliable, and complete data. They underscore the imperative of safe and secure storage and the need to enhance the ability to support the database and maintain it. Moreover, they cite data-storage integration and systems interconnectivity as being crucial to the utilization of data in one unified reporting mechanism, enhancing research capabilities and allowing for the development of policies and regulations. Stakeholders express the importance of a digitalized and integrated data collection, storage, and utilization process in the health system.

Stakeholders have not received formal training or education in health-data governance. One policymaker notes attending a workshop on data computing and automation. Regarding local data-governance laws and regulations, most stakeholders indicate that they are not available, or at least not accessible, to the public. Some policymakers say that the government has been working on regulations and strategies related to data security, data theft, and confidential sharing of digital data among ministries and various sectors.

Existing health-data practices, frameworks, and regulations

1. PROTECT PEOPLE:

The focus of this objective is to prevent exposing individuals, groups or communities to harm, and it proposes protective measures in relation to data handling.

Data Collection

In hospitals, primary healthcare clinics and labs, patients provide personal data, including name, identification number, date of birth, marital status, address, and phone number. Some clinics collect other details such as the number of household members, educational attainment, type of work, and household income. This personal data is collected using paper-based methods, digitally, or both, primarily at reception desks by administrative personnel, by midwives in some clinics, or by technicians in lab settings.

Physicians proceed with data collection, recording medical history, family history, current symptoms, relevant health habits, number of pregnancies, and number of abortions. They request specific laboratory tests and conduct clinical measurements. In hospitals, once a patient is admitted, midwives are granted access to the patient's file and are responsible for implementing the physicians' orders and writing notes of each step taken while monitoring and recording vitals, blood test results, and other clinical measurements relevant to the case, which could include cervical examination and cardiotocography.

For their part, private health insurance companies request the name, identification number, date of birth, and past medical history of their prospective policyholders, in addition to some blood tests.

On the other hand, the state health insurance authority obtains citizens' data directly from the Interior Ministry once an identification number is provided. This includes name, date of birth, and information on household members. During our interview, an employee at the government health insurance authority says,

> *"Two years ago, we started a new system. This year, it was linked with the Interior Ministry. The data gets downloaded, making it more accurate and convenient."*[27]

According to all our interviews, consent for data collection is not obtained from patients. Nor are patients provided with details regarding data storage and sharing or the opportunity to consent to either. Participants in this research nearly unanimously noted that data collection is a rou-

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[27] Public sector interview, 24 August 2023

tine and basic procedure that occurs naturally as part of their work. They also indicate that no one outside their respective facilities has access to the data, with questions asked in private settings and patients understanding the need for information to be collected.

According to one hospital administrator,

> *"The patient already knows that when they come to us, we will say: 'We will create a patient file for you.' The patient might ask about why their phone number is being requested, and we respond by telling them that a phone number is required for all patient files."*[28]

A gynecologist says,

> *"This matter of collecting information is a basic and routine procedure and part of the diagnostic process. In case we have any uncomfortable questions, we are able to avoid having anyone else present in the room."*[29]

Another gynecologist states,

> *"No, there is no consent; not even verbal consent. However, every patient is afforded privacy, and a username is required for any employee to log on to the system."*[30]

Policymakers and upper-level managers also indicate that this data-collection procedure does not require patient approval because data is not shared and is only used for statistical reports. One manager notes that when the digital system was first introduced in state clinics, healthcare providers would inform patients that their digital file was ready and would be stored, and they would then enter the patient's consent into the system. However, currently, no consent is obtained.

Data Processing

The quality-assurance measures in place for data processing include the validation and accuracy assessment of the collected and stored data, which is conducted through committee or by supervisors in health facilities. On the policymaker level, participants state that these measures are considered weak, as indicated in the following response:

> *"We have a quality-assurance committee in the hospitals, which includes a doctor, an administrator, an IT specialist, and a nurse. In some hospitals, these committees are activated, but unfortunately, in others, we need to*

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[28] Public sector interview, 3 July 2023

[29] Public sector interview, 22 August 2023

[30] Private sector interview, 23 August 2023

> *work on them. Frankly, the issue of data quality needs a lot of work."*[31]

The reports delivered monthly or annually to the Ministry of Health are reviewed and compared with previous months and years or with other data in the country:

> *"The clinic gathers data monthly. On the 10th of every month, I must receive the data. After the doctors' and nurses' supervisors review the numbers and approve them, I am able to view them at the ministry. In case I am suspicious of some data, I call them or send a message through the system, indicating that a certain number varies greatly from those of previous months."*[32]

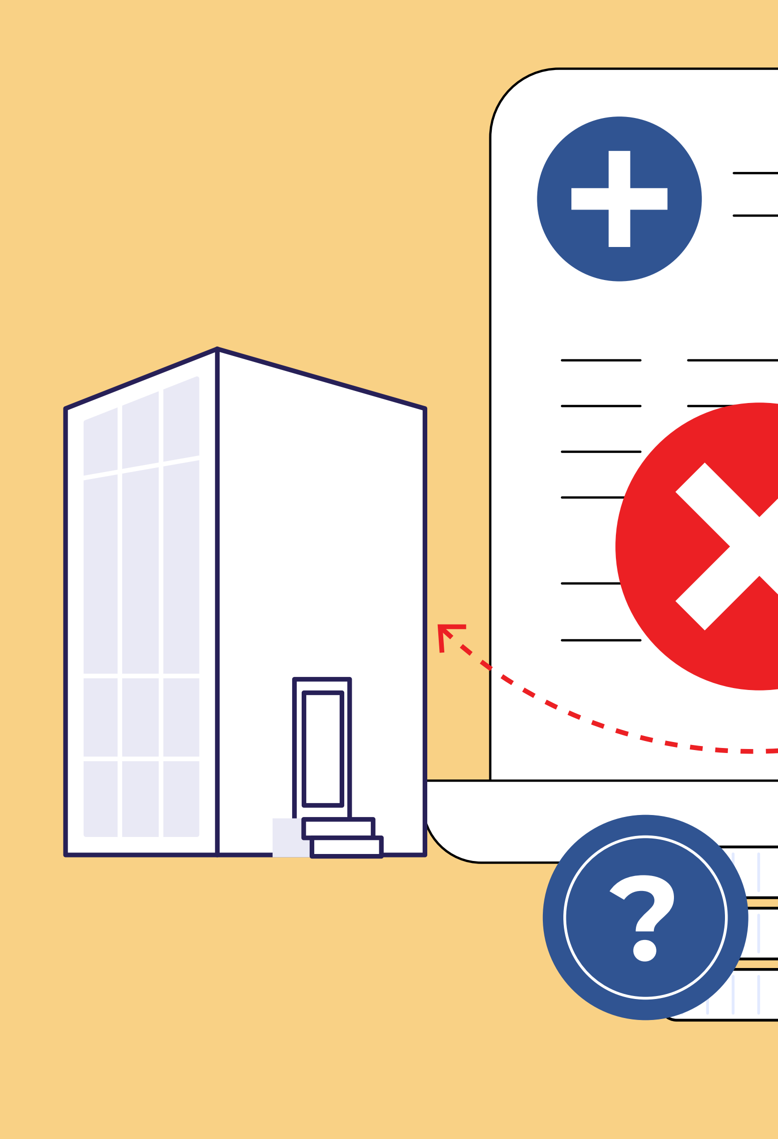
Another manager indicates that there is no supervision over the data collection process:

> *"There is absolutely no oversight. We receive [data] from all government and private facilities, and there is no oversight. For example, the hospital says that they had 20 cesarean sections. I don't have any oversight to confirm whether that number is accurate or not."*[33]

On the healthcare providers level, in hospitals, clinics and labs, department heads are responsible for data auditing. Head nurses in hospitals go through all inpatient-related notes, which is a daily task in the mornings and before patients are discharged, to provide nurses and midwives with directions for better documentation in patient files.

In labs, the supervisor or technicians are responsible for reviewing lab results to ensure that they comport with rational values. Sometimes reviews involve comparing present results against the patient's results history. Supervisors then either approve or reject the results.

The private-sector entities note their utilization of auditing committees tasked with reviewing the indicators used to measure service quality, including attendant numbers. In addition, they point to their use of the ISO quality-management system to control their work mechanisms and obtain the most accurate and reliable test results. The public sector has plans to obtain accreditation in the near future.



Data Sharing

Healthcare providers do not obtain patient consent for data collection. Participants explain that data sharing mainly occurs for governmental reporting purposes, as policymakers require it for analysis, to highlight certain statistics and trends, or for use in policy papers and planning.

Statistical data is gathered and provided in monthly or annual reports to the administration of a given health facility, including the following information as related by one midwife interviewed for this study:

> *"Age, gravida para, number of pregnancies, number of births, numbers of miscarriages, gestational age, blood type... mode of delivery, whether suction was used or if she had a perineal incision or epidural... the baby's gender... without the name of patients, just a count for the number of patients*

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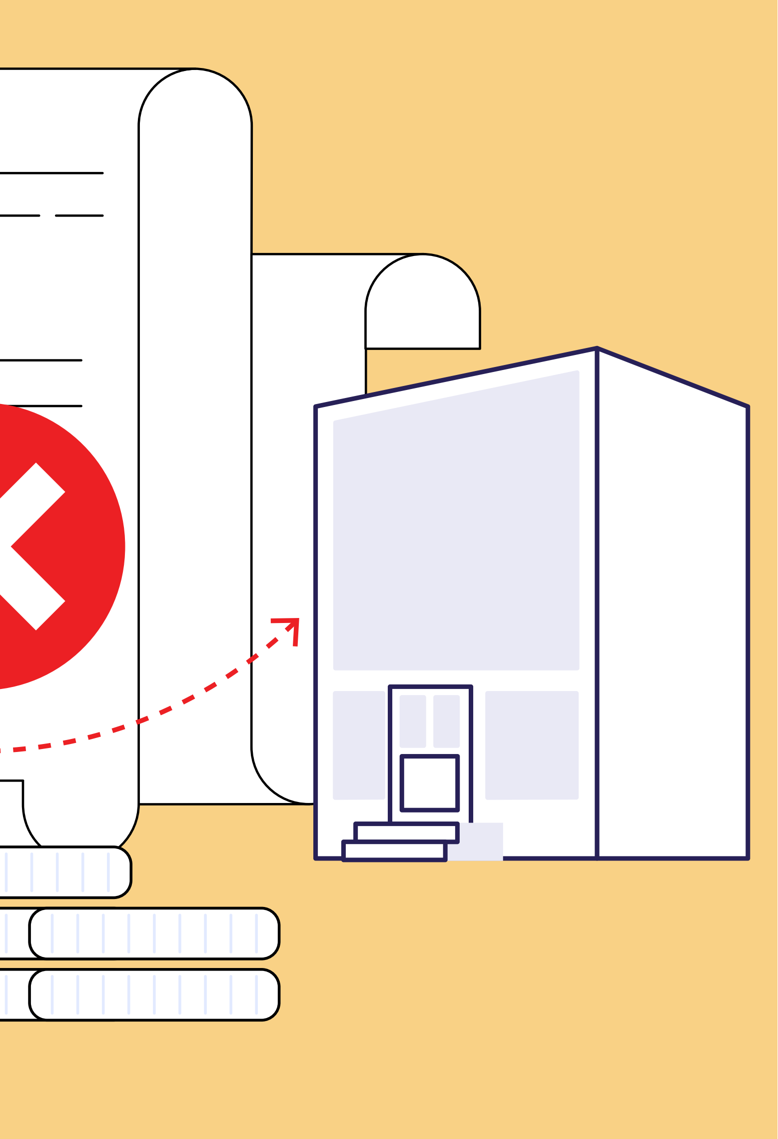
[31] Public sector interview, 30 August 2023

[32] Public sector interview, 10 May 2023

[33] Public sector interview, 6 July 2023



> *and the number of cesarean sections for example.”*[34]

Another midwife recounts asking,

> *“the number of admissions, number of births stratified based on weight, mode of delivery and gender, number of premature infant cases, [and] number of children admitted to a nursery.”*[35]

One policymakers cites an example, saying,

> *“we have an annual report for maternal deaths, which does not provide personal data to ensure confidentiality; the types of data include past and recent surgical history, services provided (with timeframe), potential delays or medical errors, complications... And this report is delivered to a national committee for review.”*[36]

Private laboratories share data based on test-specific Ministry of Health instructions. Health insurance providers indicate that no one has access to their data, which is not shared with or accessible to any external entity.

As for data sharing for research purposes, it is mostly not possible, according to most of the healthcare providers we interviewed. Policymakers state that data sharing requires approval on multiple levels after a formal request is filed with specific stakeholders. If a request is approved, only numerical data is provided for analysis, with no personal identifying information contained therein.

> *“We understand from the researcher precisely what information is needed. I then provide the numbers only. If they want data from any governorate, we could provide it, but without any personal details.”*[37]

Data Storage

Generally, in all public and private entities, a combination of storage methods is utilized; paper documents are stored in archives for several years, and digital data is entered into systems and stored on servers. In the public sector, the central database is maintained in a data center at the Ministry of Health, but not all public-health facilities utilize digital methods.

Data Security

To ensure the security of stored data, respondents affirm that each worker has a username and password which can only be used within the health facility. One security feature employed by the entities we interviewed is automatic logout due to session timeout. The private lab sector indicates that the system was developed to contain encryption and a firewall. A private insurance office indicates that their paper documents are protected and archived in a secure location.

Regarding access to data, in healthcare facilities, each worker is granted access in accordance with their scope of work. Generally, reception workers can only view the personal data required to open a new patient file, physicians have full access to their patient files, and midwives have access once the patients are admitted. As for data editing, it is available for inpatients but becomes inaccessible once the patient leaves the facility.

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[34] Private sector interview, 21 August 2023

[35] Public sector interview, 15 August 2023

[36] Public sector interview, 10 May 2023

[37] Public sector interview, 6 June 2023

In labs, all technicians and managers have access to patients' files and data, but editing is not available once the test results are approved. Upper-level managers receive read-only reports of the data, which mainly consist of frequency tables and no identifying information.

2. PROMOTE HEALTH VALUE

This objective concerns enhancing the health outcomes of individuals and the community through data utilization and analysis to obtain maximum value.

Data Collection

With regards to interoperability across all entities, public or private, respondents indicate that as long as data is digitized, retrieving files and information is easily done. In terms of data-collection methods, healthcare facilities can be categorized as follows:

1) Digital-analog combination: Most public and private entities use a combination of paper-based and digital data-collection methods. "We are not able to dispense with paper documents," say several stakeholders. Paper forms are used for monitoring inpatients' vitals, blood sugar profiles and other health data such as blood-type labels used for blood transfusion purposes. In labs, sheets are used for the convenience of knowing which tests have been ordered and for recording results. Digital files include personal and medical information, history, current diagnosis, and test results, in addition to medical staff notes and scanned monitoring test documents.

2) Exclusively digital, e.g. as in governmental insurance.

3) Exclusively paper-based: in some primary, public-sector healthcare clinics, which provide women's-health and family-planning services, only paper forms are used and then stored in archives.

In case of power outages or technical system-level issues, paper forms are used. If the digital system is restored while the patient is still in the health facility, data is digitally synchronized with the database. However, this synchronization option is not available in some outpatient clinics.

Modes of data delivery from public- or private-sector health entities to policymakers are not unified and depend on the types of data and whether they are stored digitally or on paper. The frequency of delivery is either monthly, annual or per the request of the Ministry of Health. Irrespective of collection method, each healthcare facility gathers data in one report and delivers it to the department of statistics at its governorate's respective directorate of health. Subsequently, each governorate delivers a digital report with statistical data to the Ministry of Health.

Data Processing

Though public-sector healthcare providers prefer using their digital system, which they say is less time consuming and allows for easy data retrieval, they identify several problems that increase workloads for them and waiting times for patients.

The system is very slow, making data entry difficult and inefficient. Healthcare providers are not certain of the cause but indicate that the devices and software being used are outdated and lack the capacity to handle the data and workload.

The system is prone to failure at any given time.

Data is not saved reliably, and medical staff sometimes need to re-enter it.

Doctors identify workload and time-constraint issues as hindrances to writing complete reports. For their part, midwives also complain about the inadequate medical information and documentation contained in admitted patients' files during antenatal care.

The use of two data-collection methods (digital and analog) places a high burden on personnel while also yielding data duplication. A head nurse in one hospital complains about this duplication amid staff shortages and work overload. One policymaker refers to this workload as being "unjust" for midwives and nurses.

The lack of human and financial resources is noted, directly and indirectly, by respondents during our interviews. Several stakeholders observe that the sustainability of healthcare systems is not guaranteed, as donors are the main providers for these systems. Furthermore, there are disparate, non-interlinked health-data systems among organizations:

> *"This is one of the big obstacles: if a patient is admitted and treated in a hospital then visits another healthcare facility or a clinic for a routine follow up or to receive medication, their file will not be seen by the doctor because the systems are not linked. Or, if the patient had been admitted to hospi-*

> *tal for something urgent, [the facility or clinic] will not have access to what health services they received."*[38]

> *"For example, if a general practitioner requests tests, I'm not able to view them and know the results and her health status, unless she provides the information on paper (lab tests, diagnosis, etc.). That's why we give her a notebook, like her own file, with all the information about her in it, so that wherever the patient goes, the doctor will know everything about her."*[39]

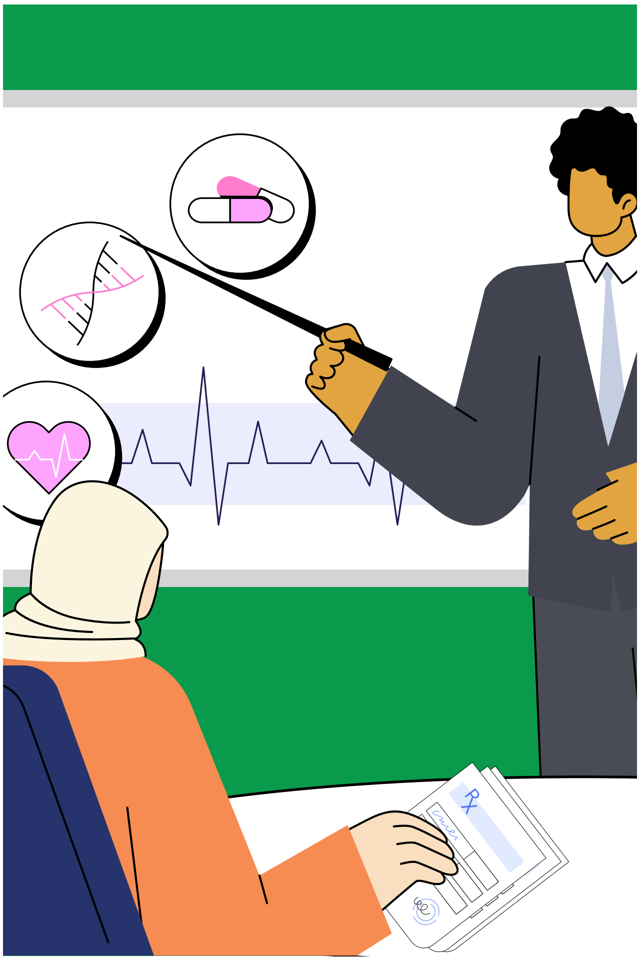
Health-data delivery to policymakers presents a challenge, as not all health facilities communicate their data. When they do, it is limited to the number of admissions and beds. In addition, the data is not delivered on time, which causes delays to the release of annual reports. Furthermore, delivered data related to women's health is incomplete and often inaccurate. For example:

"Among the challenges is the way in which death certificates are prepared and put out. Unfortunately, healthcare personnel are not aware of the importance of entering accurate data. Of course, this is an issue that sometimes arises due to workload pressure."[39]

Policymakers regard these issues as obstacles to effective data utilization and interpretation, hindering policy and strategy development. Another internal problem arises from the delay in granting usernames and passwords for new staff members, as one head nurse notes:

> *"For example, I have an employee who has been working for more than a year and a half without [login] credentials... she accesses the system using her colleagues' usernames, and once she registers the data, she signs her name."* [40]

Innovative data-handling mechanisms can aid in overcoming the challenges faced in the Palestinian healthcare system. Stakeholders' recommendations focus mainly on the need to obtain new computer devices and fully adopt digital data entry using a system that is up to date and fast. They also call for enhancing data quality by providing training on accurate data collection and storage, in addition to developing a unified digitalized system, with data stored on one server.



One policymaker believes that in order to change a policy or make a new regulation, recommendations from academic institutions are essential and should be translated and published in the Arabic language:

> *"I hope that training will be provided, top to bottom, on data management, governance, utilization, and on the importance of data."* [41]

One stakeholder notes the importance of family medicine and creation of a medical file for each individual:

> *"We are very ambitious and aspire to digitalize systems and have a digital file for every patient in the country."*[42]

The private lab sector has initiated a fingerprint patient-identification system to avoid duplicate files and to minimize the chances of overlap due to commonly recurring Arabic names. While governmental insurance is linked with the Ministry of Interior, this is not the case in all public health facilities, as one hospital administrator

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[38] Public sector interview, 6 June 2023

[39] Public sector interview, 24 August 2023

[40] Public sector interview, 15 August 2023

[41] Public sector interview, 10 May 2023

[42] Public sector interview, 6 June 2023

suggested this feature of having an electronic link between the Ministry of Health and the Ministry of Interior to save time and ensure the accuracy of data collected. The private insurance company that we interviewed is working toward initiating a computerized program, discarding all paper documents, except for registration forms.

Most of the healthcare providers we interviewed have limited knowledge about current digital advances. Machine learning and AI are currently not used by Palestinian healthcare organizations. One gynecologist believes that these advances might be helpful in recording accurate notes directly during medical consultations to guarantee comprehensive data collection, e.g. autocorrect, error detection, etc. From the policymakers' perspective, implementing these digital advances cannot be considered before enhancing the healthcare system infrastructure, digitizing all data, collecting valid and reliable data, and linking and sharing data among different sectors. As there are other complications to consider and work toward redressing, policymakers believe that organizations in Palestine are far from introducing digital advances:

> *"It is unreasonable to begin seeking artificial intelligence in a situation where it would take me six months to receive a mouse if I requested one for my desk... The biggest challenge is how we prepare ourselves for the future. We should have a clear legal infrastructure. At some point, we will go for AI, because the whole world is heading there. But within our current reality, I have many priorities that are much more important than AI: the security of my data is very important; the quality and accuracy of data are very important; and utilizing data is much more important. At the current stage, analyzing the data and health indicators that I can see through the data I collect is much more important to me than AI... There is also the issue of funds for capacity building and investment in human resources."*[43]

The beneficial role of AI in healthcare from the perspective of policymakers includes data interpretation and analysis toward assessing and forecasting the health status of the Palestinian population and issuing recommendations to protect against diseases. Another potential role noted by the insurance sector is fraud prevention, namely detecting when patients take medications that are unrelated to their health conditions and diagnoses.

Data sharing

Data sharing among healthcare facilities and providers needs to be enhanced in the Palestinian context. Firstly, informed patient consent should be officially obtained prior to data sharing, a core component of the health value promotion principle. Interviewees from public and private health facilities state that non-identifying patient data is shared with the Ministry of Health for the purpose of publishing an annual report. The resulting statistics are obtained by the ministry's policymakers and used for planning and policy making. This process, however, is hindered by several issues, including incomplete data that lacks substantial essential information about patients' health status, in addition to insufficient data being provided by private-sector entities, according to several ministry policymakers.

Moreover, the healthcare system lacks rules and guidelines on how data sharing for research purposes should be conducted, as indicated by the inconsistent responses in that regard, with some policymakers noting that data is shared per researchers' requests. It is clearly indicated that for researchers to obtain data from the Ministry of Health, they are required to submit an official request from their affiliated entity and can only obtain raw, non-identifying data after they are granted approval. Private-sector entities state that they only share data with the Ministry of Health based on their request, and they do not provide data for research purposes as far as the stakeholders we interviewed know.

Data Storage

Partnerships and interoperability between the Palestinian public- and private-healthcare sectors and among the entities that comprise them are limited and should be enhanced and supported, prioritizing individuals' health and society's interest. Linkage among healthcare entities should be established in a structured way and based on clear policies. For instance, only the public health insurance system is linked with the Ministry of Interior, allowing the sharing of some data.

3. PRIORITIZE EQUITY

This objective calls for an equitable distribution among all individuals and communities of the benefits derived from data.

Data Collection

In order to mitigate data bias during data collection, head nurses are responsible for reviewing

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[43] Public sector interview, 30 August 2023

midwives and nurses' notes, and lab supervisors review lab results before approval. Healthcare providers understand the importance of collecting complete, accurate, and truthful data from all patients. All individuals at any health facility are required to provide personal and medical data, but based on stakeholders' responses, there appear to be issues around missing data and incomplete field entries, hindering the formation of complete datasets. [44]

One policymaker indicates that the government is working to implement a computerized health-data-entry system. There is unanimity among the policymakers as to the imperative that collected data always be of high quality, with one noting that,

> *"data must be complete and reliable, meaning it must be accurate, consistent, with no duplication."* [45]

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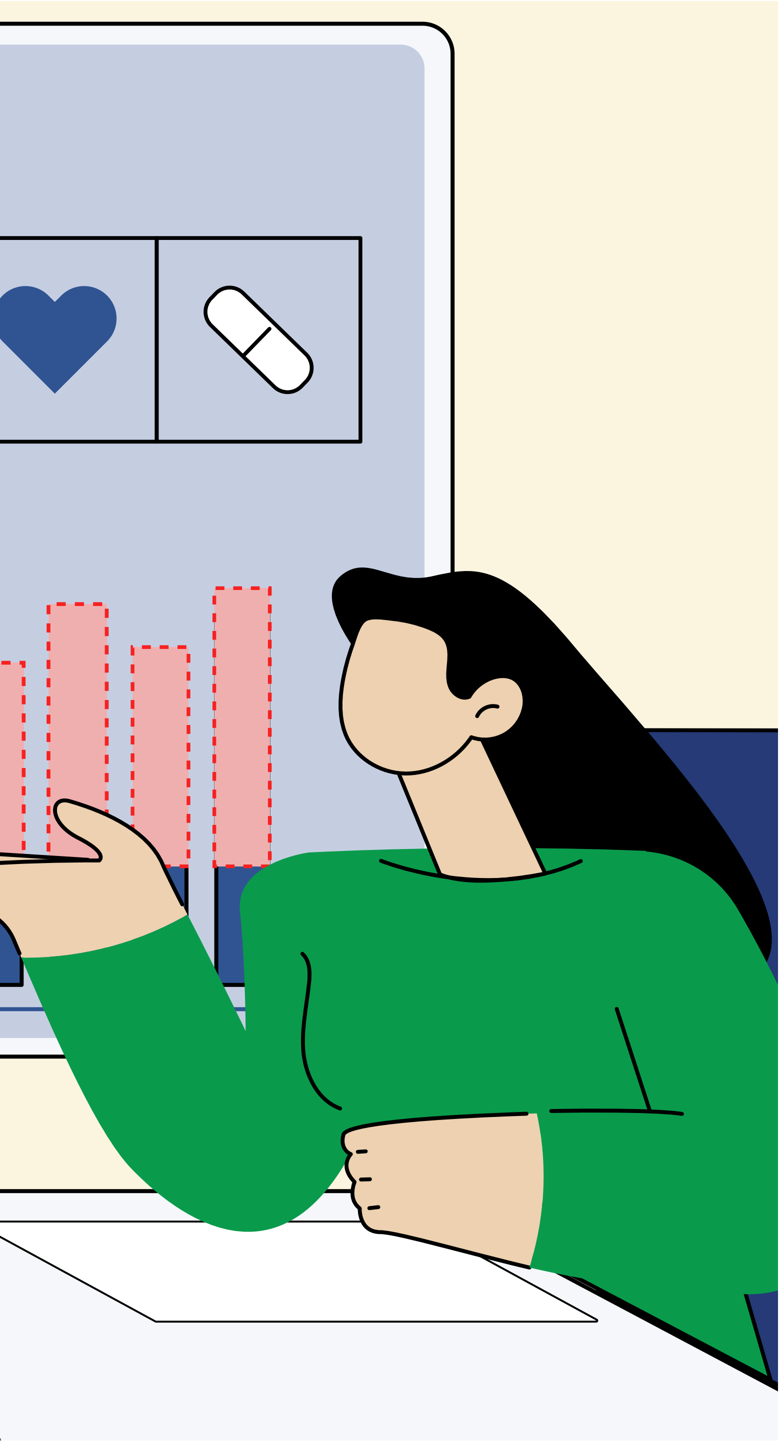
[44] Public sector interview, 30 August 2023



> *"The truth is that everyone must be trained. Everyone must understand the value of data."* [45]

Data Processing

The main obstacle in this regard is the unavailability of data from across health facilities. One stakeholder explains, "The problem we have is that there is no integrated connectivity. For good governance, data from governmental and non-governmental entities must be available in order to complete the circle. Data should be collected in one place in order to create one central database."[46]

Data Sharing

Policy makers underscore the importance of good-quality data that can be analyzed and utilized in making decisions, setting budgets, planning, and writing implementable policies. Since the sharing of health data is beneficial to the population and decision makers, it should be done in a way that is coherent and useful, argues one policy maker .

Data Storage:

There is a lack of health-data cooperatives to define the rules of data storage in Palestine:

> *"We faced a problem when we referred to Palestinian law; within the bounds of our knowledge and consultations, we did not find any law that protects medical information."*[47]

> *"They tell you that there must be a mechanism to save this data; they don't care if it is verbal or on paper. The important thing is that you must find a mechanism and abide by it. We do not have any controls or laws"* [48]

V. ANALYSIS AND TAKEAWAYS

One of the main findings of this study is our inability to identify any rules and regulations that govern the existing health-data practices, reflecting similar findings of a 2018 study conducted in Palestine and published by *The Lancet*.[49] Another 2018 qualitative study, involving Palestinian experts in the healthcare system and published in *Health Research Policy and Systems*, concluded that there is an imperative need for a governing body and policies to improve and support the performance of the healthcare system.[50] Further, a 2020 research published in *Global Public Health* addressed the need for national policies and health-sector collaboration, illustrating how the weak governance of the

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[45] Public sector interview, 10 May 2023

[46] Public sector interview, 6 July 2023

[47] Private sector interview, 30 August 2023

[48] Private sector interview, 29 August 2023

[49] Myhre, Sonja, et al. "Governance Guidance for an eRegistry for Maternal and Child Health: Lessons from the Occupied Palestinian Territory." *The Lancet* 391 (2018). S35. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)30360-X/fulltext

[50] AlKhaldi, Mohammed, et al. "Assessing Policy-Makers', Academics' and Experts' Satisfaction with the Performance of the Palestinian Health Research System: A Qualitative Study." *Health Research Policy and Systems* 16, no. 1 (2018): 1–11. https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-018-0341-x

healthcare system was revealed in the response to the COVID-19 pandemic.[51]

Stakeholders interviewed in our study indicate that there have been recent governmental efforts toward developing data-management regulations. This is evident in the Ministry of Health's strategic plans, which note the need to establish standardized procedures for handling data, with the aim of eventually utilizing and benefitting from it.[52]

Palestine's health sector is supported by reproductive health and e-health strategies, monitoring systems for women's health indicators, and the digitalization of several sub-sectors. However, this research identified many challenges and limitations in the healthcare system.

The use of information technology is neither systematic nor organized. As a result of the system's unstructured nature, data on the population's health is collected, processed, shared and stored using disparate methods, including a combination of paper-based and digital processes. Most respondents argue that paper documents are frequently used to guarantee that data is not lost, or due to the difficulty that poor internet connectivity in hospital rooms poses to the use of online patient monitoring devices, among other reasons. Consequently, some data is collected through both methods, resulting in duplicated processes and overburdening healthcare providers. This issue has been addressed in the health section's Information Strategic Plan, which aims to gradually bolster the information systems and computerized health systems. The use of duplicated data-entry methods in some facilities leads to inconsistent data reporting to the Ministry of Health, as indicated by various stakeholders' responses regarding this matter.

Stakeholders' knowledge of health-data governance and the principles of data management is based on convention rather than written legislation. In addition to healthcare providers being trained only in data entry, such training is only received when a new program is introduced, and trained personnel are expected to train new staff. None of the participants mention being involved in training on data handling, protection, security and utilization.

The main challenges identified in the healthcare system by the study are the lack of resources, the influence of donors' agendas on the disbursement of funds, and the lack of an adequate infrastructure for a digitalized system. Additionally, there is a need to enhance collaboration among different sub-sectors. These findings were also reflected in publications by the World Health Organization.[53,54]

In view of these matters, the stakeholders underscore the importance of: having a sustainable healthcare system that keeps up with current developments in information technology; integration among all health sectors to maximize the utility and benefits of data; the need for high-quality, accurate data; and linking healthcare facilities with the Interior Ministry. Healthcare providers also express a dire need for updated digital systems to enhance their present workflow.

Interpretations of each principle:

1st principle: Protect people

Regulations and laws with specialized measures to address protection in data practices are lacking. Health data is protected in current systems using secured software, server storage mechanisms for digital data, and archives for paper files. Data collection is not done with informed consent, despite the stakeholders noting that data is utilized for research and published reports.

Data quality is monitored by supervisors in the health facilities. This is a limited measure, however, due to the inability to make edits or changes if an error is identified after patients are discharged. Most policymakers are not confident in the accuracy of the data that is reported.

The 2nd principle: Promote health value

The value of data obtained from the healthcare system should be maximized by ensuring its quality, unifying the dataset, promoting the entry of complete and accurate data, analyzing data and utilizing it down the line to improve health services and outcomes.

The process of data utilization with the aim of enhancing the healthcare system and its services should be developed on several levels:

1) High-quality and complete data collection should be promoted.

2) Healthcare workers should be involved in the improvement of programs. This has been initiated in one of the private sector entities surveyed

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[51] AlKhaldi, Mohammed et al. "Health System's Response to the COVID-19 Pandemic in Conflict Settings: Policy Reflections from Palestine," *Global Public Health* 15, no. 8 (2020): 1244–56. https://pubmed.ncbi.nlm.nih.gov/32552389/

[52] Palestinian Ministry of Health, *Health Sector Strategic Plan: Southern Governorates 2021–2025* (2021). https://www.moh.gov.ps/mohStatL/E_Strategic_Plan_2021-2025.pdf

[53] World Health Organization. "eHealth and Innovation in Women's and Children's Health: A Baseline Review: Based on the Findings of the 2013 Survey of CoIA Countries by the WHO Global Observatory for eHealth" (March 2014). https://iris.who.int/handle/10665/111922

[54] Abu El Kheir-Mataria, Wafa. "Enhancing Ministry of Health-NGOs Partnership in Palestine for Effective Health Services Delivery: Advancing Towards Universal Health Coverage." https://www.emro.who.int/images/stories/rpc/Research_in_priority_areas_of_public_health/rpph-18-88.pdf?ua=1

for this study, which noted that most innovative ideas to enhance workflow have emerged from the workers themselves. Such improvements, however, should be implemented on the policies and regulatory levels.

3) Inter-sectoral collaboration should be promoted.

The use of artificial intelligence in the healthcare system is near absent on both the policy and practical levels due to the need to strengthen the digital data infrastructure.

3rd principle: Prioritize equity

Data collected from all individuals is treated equitably and there is no distinction based on any social, gender-based, regional factors. However, the main equity issue lies in incomplete data entry. Stakeholders agree on the importance of utilizing data to benefit the population and enhance health services for all patients, but that the main challenge is the lack of policies to regulate the data-collection process. While clear processes for data sharing are necessary, responses regarding the possibility of benefiting from health data through research are not consistent; nor is there a clear definition of the types of data that could be shared for this purpose or the approach for doing so.

VI. LIMITATIONS

The main limitations of this study were the logistical processes required for arranging interviews with stakeholders, insufficient awareness of data governance among interviewees, and inconsistent responses.

VII. CONCLUSION

This study examined the governance landscape in terms of current practices and frameworks related to women's health data and evaluated the awareness of different stakeholders regarding health-data governance in Palestine. A qualitative approach was utilized using in-depth semi-structured interviews with policymakers, mid-level managers and healthcare providers using a theoretical framework that was developed in accordance with the World Bank's Health Data Governance Principles.

The main findings of this research indicate an imperative need to advocate for the development and implementation of national policies and regulatory frameworks for health-data handling; develop all health facilities' information-technology infrastructure; promote collaboration among different healthcare sub-sectors; and implement capacity-building programs.

VIII. POLICY-ORIENTED RECOMMENDATIONS

1) **Strengthening governance:**
   - Advocate for the development and implementation of national policies and regulations governing health-data handling practices.
   - Encourage the establishment of a comprehensive regulatory framework covering data collection, processing, storage and sharing across all health sectors.
2) **Capacity building:**
   - Implement training programs focused on the principles of health-data handling for practitioners and policymakers.
   - Stress the importance of enhancing knowledge and skills related to data governance to ensure compliance and standardized practices.
3) **Promoting collaboration:**
   - Recommend initiatives to promote collaboration among different healthcare sectors through data sharing.
   - Emphasize the benefits of integrated health information systems to improve communication and coordination among healthcare providers.
4) **Infrastructure development:**
   - Advocate for the development and integration of information-technology infrastructure in health facilities.
   - Highlight the need for standardized electronic health information systems to improve efficiency and reduce workflow burdens.

APPENDIX

APPENDIX A: THE STATE OF DATA GOVERNANCE IN WOMEN'S HEALTH — FIELDWORK INTERVIEW QUESTIONS

Interview questions for healthcare professionals/settings:

Section 1: Data governance in healthcare

1) In your opinion, what are the main principles/pillars of data governance in healthcare? (*need to give probing questions here if they are not aware of them: protect people, promote health, and prioritize equity*)

2) What is the importance or purpose of data governance in healthcare, and how could it be achieved?

3) What, in your opinion, are the risks of inadequate data governance in healthcare?

4) How familiar are you with your local data governance laws and regulations (your setting, the country, etc.)? What do you know about them?

5) Have you received any formal training or education on data governance? Describe the content and the provider of this training.

Section 2: Data acquisition, storage, security, and protection

6) Please provide an overview of patients' experience within your setting (from entering the health facility until they leave).

7) Who is responsible for patients' data collection in your setting (administrator, nurse, physician, etc.)?

8) What types of data do you collect from the patient? (personal data, insurance details, social history, medical history, etc.).

9) How do you collect patients' data? (offline, using paper, digitally, computers/tablets, etc.).

10) Which data-collection method do you implement for each type of data? Is the same data captured using both offline and digital methods?

11) Do you have one database for all collected data? Is that the case for all types of data?

12) If different methods are used to collect different data, how and when is the data synchronized in your databases?

13) How and where do you store your patients' data? (onsite computers, online servers, file archives, etc.).

14) What measures, if any, are taken to validate the quality and accuracy of the collected and stored data? Are you responsible for quality control? If not, who is?

15) Who has access to view/edit patients' data?

16) What measures do you take to ensure the security of the patients' collected data (two-factor authentication, encryption, cloud servers, de-identification, etc.)? What policies are in place to mitigate security threats?

17) What type of health data (medical history, signs and symptoms, etc.) and clinical measurements (hemodynamics, laboratory tests, etc.) do you collect from your patients?

18) In repeat visits, do you retrieve patients' data from your files, or do you record their data again?
19) Do you obtain patients' consent to collect, use, store and share their data?
    - If yes, how do you obtain it (verbal consent, written forms, etc.)?
    - If not, please specify the reason.

20) Is patient data shared with third parties? (insurance companies, etc.). If yes:
    - What type of data is shared?
    - Who is it shared with? (insurance companies, researchers, other providers, etc.)
    - How is it shared? (over the phone, online correspondence, etc.)
    - What measures are there to protect the privacy of your patients' data if it is being shared (anonymization, encryption, limited access, etc.)?

Section 3: Health data governance challenges and potential solutions

21) What data-related problems does your organization face? What are the main challenges that you have identified in the governance of women's health data?

22) What recommendations do you propose to overcome these challenges?

23) Do you believe that current digital developments, such as artificial intelligence (AI) and machine learning, can help overcome these challenges?

24) Do you use any of these digital developments (AI) in your current work?

25) In your opinion, what are the biggest challenges to the use of AI and machine learning in healthcare?

Interview questions for policymakers/insurance personnel/administrators:

Section 1: Data governance in healthcare

1) In your opinion, what are the main principles/pillars of data governance in healthcare? (*need to give probing questions here if they are not aware of them: protect people, promote health, and prioritize equity*)

2) What is the importance or purpose of data governance in healthcare, and how could it be achieved?

3) What, in your opinion, are the risks of inadequate data governance in healthcare?

4) How familiar are you with local data governance laws and regulations? What do you know about them?

5) Have you received any formal training or education on data governance? Describe the content and the provider of this training.

Section 2: Data governance practices

6) Please explain the different administrative roles in your setting.

7) How and where do you obtain/retrieve patients' data? Are any of the data you collect considered sensitive? If yes, please provide some examples.

8) What is the workflow of the collected patient data? Explain the sequence of tasks performed by the different people within and across your organization.

9) What measures are in place to ensure the privacy of patients' data (anonymization, encryption, etc.)? Are these data viewable or recognizable?

10) How do you store your patients' data (cloud servers, local computers, paper files, etc.)? Please describe your data storage infrastructure.

11) Do you encounter errors in data entry (entering data into wrong fields or entering wrong numbers)? How do you remedy this?

12) What measures, if any, are taken to validate the quality and accuracy of the collected and stored data? Do you think that using technologies like AI and machine learning could help in the quality check of data? If yes, how? If not, why not?

13) How do you ensure the data is up to date? Is there a way to update patients' records?

14) Who has access to view and/or edit patients' data on the individual and entities levels?

15) What measures do you take to ensure the security of the collected/stored patient data (two-factor authentication, encryption, cloud servers, de-identification, etc.)? OR what policies are in place to mitigate security threats in the storage and retrieval of data?

16) What type of data, if any, do you share with external individuals and/or entities? Please mention any parties with whom you share the data.

17) How do you share patients' data with third parties (over the phone, online correspondence, etc.)? What measures are there to protect the privacy of your patients' data if being shared?

18) How do you obtain the patients' consent to collect, use, store, and share their data (verbal consent, written forms, etc.)?

Section 3: Health data governance challenges and potential solutions

19) What data-related problems does your organization face? What are the main challenges that you have identified in the governance of women's health data?

20) What recommendations do you propose to overcome these challenges?

21) Do you believe current digital advances (AI and machine learning) can help in overcoming these challenges?

22) Do you use or plan to introduce AI in the system? (elaborate)

23) In your opinion, what are the biggest challenges to the use of AI and machine learning in healthcare?

24) Do you anticipate the use of digital advances like AI in healthcare in the future?

APPENDIX B: INTERVIEW QUESTIONS AND THEIR CORRESPONDING HEALTH DATA GOVERNANCE PRINCIPLES

Health Data Governance Principles by World Bank 2022			Question
DATA COLLECTION			
P.1. Protect People	P.1.1 Protect individuals and communities	Collect data with defined purposes	What types of data do you collect from the patient? (personal data, insurance details, social history, medical history, etc.).
			What type of health data (medical history, signs and symptoms, etc.) and clinical measurements (hemodynamics, laboratory tests, etc.) do you collect from your patients?

		Collect personal/sensitive data with informed consent	Do you obtain the patients' consent to collect, use, store and share their data? If yes, how do you obtain it (verbal consent, written forms, etc.)? If not, please specify the reason.
		Secured data collection mechanism: Data collection methods with robust data collection functionability	What measures do you take to ensure the security of the patients' collected data (two-factor authentication, encryption, cloud servers, de-identification, etc.)? What policies are in place to mitigate security threats?
	P.1.2 Build trust in data systems	Inclusive data collection mechanisms	
		Ensure consent is informed	Do you obtain the patients' consent to collect, use, store and share their data? If yes, how do you obtain it (verbal consent, written forms, etc.)? If not, please specify the reason.
		High quality and accurate data collection processes	What measures, if any, are taken to validate the quality and accuracy of the collected and stored data? Are you responsible for the quality check? If not, who is?
	P.1.3 Ensure data security	Ensure data security in data collection practices	Who has access to view and/or edit patients' data?
			What measures do you take to ensure the security of the patients' collected data (two-factor authentication, encryption, cloud servers, de-identification, etc.)? What policies are in place to mitigate security threats?
P.2. Promote Health Value	P.2.1 Enhance health systems' services	Increase community engagement during data collection	
		Empower frontline health workers by continuously building their skills to support their data collection methods	
	P.2.2 Promote data sharing and interoperability	Use previously collected data to reduce the need of new data collection	In repeat visits, do you retrieve patients' data from your files, or do you record their data again?
		Data collection systems to be designed with interoperability in mind	

		Define common data structures (e.g., specific fields for data collection)	Which method of collection do you use for each type of data? Is the same data captured using offline and digital methods?
			If different methods are used to collect different data, how and when are the data synchronized in your databases?
	P.2.3 Facilitate innovation using health data	New types of policies are needed for innovative collection of health data	What data-related problems does your organization face? What are the main challenges you have identified in the governance of women's health data?
			What recommendations do you propose to overcome these challenges?
			Do you believe current digital advances (AI and machine learning) can help in overcoming these challenges?
			Do you use any of these digital advances (AI) in your current work?
			In your opinion, what are the biggest challenges to the use of AI and machine learning in healthcare?
P.3. Prioritise Equity	P.3.1 Promote Equitable Benefits from Health Data	Inclusive data collection methodologies that consider which individuals/groups are asked to provide data, which data categories are collected and what is the use of the collected data	
		Cross-cutting data collection along categories like gender, sex, age, socio-economic status, abilities, citizenship status, class, race, and ethnicity	What types of data do you collect from the patient? (personal data, insurance details, social history, medical history, etc.).
			What type of health data (medical history, signs and symptoms, etc.) and clinical measurements (hemodynamics, laboratory tests, etc.) do you collect from your patients?
		Mitigate data bias in health data collection	What measures, if any, are taken to validate the quality and accuracy of the collected and stored data? Are you responsible for quality check? If not, who is?
		Individuals involved in data health data collection, e.g., frontline health workers should understand the purpose of data use	Who is responsible for patients' data collection in your setting (administrator, nurse, physician, etc.)?

			Is the patient data shared with third parties? (insurance companies, etc.). If yes: - What type of data is shared? - Who is it shared with (insurance companies, researchers, other providers, etc.)? - How is it shared (over the phone, online correspondence, etc.)? - What measures are there to protect the privacy of your patients' data if being shared (anonymization, encryption, limited access, etc.)?
	P.3.2 Establish Data Rights & Ownerships	Develop health data trusts and health data cooperatives to define rules of data collection	How familiar are you with local data governance laws and regulations (your setting, the country)? What do you know about them?
			In your opinion, what are the main principles/pillars of data governance in healthcare? (need to give probing questions here if they are not aware of them: protect people, promote health, and prioritize equity)
			What is the importance or goal of data governance in healthcare, and how could it be achieved?
DATA PROCESSING			
P.1. Protect People	P.1.3 Ensure Data Security	Strong technical security measures for data processing (e.g., data security audits)	What measures, if any, are taken to validate the quality and accuracy of the collected and stored data? Are you responsible for quality check? If not, who is?
		Consider federated data processing across the health system	
P.2. Promote Health Value	P.2.3 Facilitate Innovation using Health Data	New types of policies are needed for innovative processing of health data	Do you believe current digital advances (AI and machine learning) can help in overcoming these challenges?
			Do you use any of these digital advances (AI) in your current work?
			In your opinion, what are the biggest challenges to the use of AI and machine learning in healthcare?
P.3. Prioritise Equity	P.3.1 Promote Equitable Benefits from Health Data	Mitigate data bias in health data processing	What measures, if any, are taken to validate the quality and accuracy of the collected and stored data? Are you responsible for quality check? If not, who is?

	P.3.2 Establish Data Rights & Ownerships	Develop health data trusts and health data cooperatives to define rules of data processing	How familiar are you with local data governance laws and regulations (your setting, the country)? What do you know about them?
			In your opinion, what are the main principles/ pillars of data governance in healthcare? (need to give probing questions here if they are not aware of them: protect people, promote health, and prioritize equity)
			What is the importance or goal of data governance in healthcare, and how could it be achieved?
DATA SHARING			
P.1. Protect People	P.1.2 Build Trust in Data Systems	Data subjects may accept or decline further sharing of their data for purposes other than its initial intended use	
	P.1.3 Ensure Data Security	Consider federated data systems across the health system for cross-system sharing and learning	Is the patient data shared with third parties (insurance companies, etc.)? If yes: - What type of data is shared? - Who is it shared with? (insurance companies, researchers, other providers, etc.) - How is it shared? (over the phone, online correspondence, etc.)
P.2. Promote Health Value	P.2.1 Enhance Health Systems Services	Enhance data sharing between health facilities and health providers for improved health services	Is the patient data shared with third parties (insurance companies, etc.)? If yes: - What type of data is shared? - Who is it shared with (insurance companies, researchers, other providers, etc.)? - How is it shared (over the phone, online correspondence, etc.)?
			What measures, if any, are taken to validate the quality and accuracy of the collected and stored data? Are you responsible for quality check? If not, who is?
	P.2.2 Promote Data Sharing & Interoperability	Establish data sharing rules and guidelines	What measures are there to protect the privacy of your patients' data if being shared (anonymization, encryption, limited access, etc.)?
		Validate informed consent before sharing data	Do you obtain the patients' consent to collect, use, store and share their data? - If yes, how do you obtain it (verbal consent, written forms, etc.)? - If not, please specify the reason.

		Promote interoperability (through recognised standards, e.g., basic data fields, and open system design) of data systems for simpler and more secure data sharing between systems (especially during manual data transfers)	
		Define common data structures (underlying architecture of data systems) across health systems to support data sharing	
		Define multiple levels of data access to minimise the risk of exposure with maximising sharing	Who has access to view and/or edit patients' data?
		Use common definitions and global standards for greater standardisation and comparability of health data and greater systems interoperability	
		Support multi-sector partnerships	
P.3. Prioritise Equity	P.3.2 Establish Data Rights & Ownerships	Develop health data trusts and health data cooperatives to define rules of data sharing	How familiar are you with local data governance laws and regulations (your setting, the country)? What do you know about them?
			In your opinion, what are the main principles/pillars of data governance in healthcare? (need to give probing questions here if they are not aware of them: protect people, promote health, and prioritize equity)
			What is the importance or goal of data governance in healthcare, and how could it be achieved?
DATA STORAGE			
P.1. Protect People	P.1.1 Protect Individuals & Communities	Use secure data storage mechanisms (e.g., encryption, cloud servers)	How and where do you store your patients' data? (onsite computers, online servers, file archives, etc.).
			What measures do you take to ensure the security of the patients' collected data (two-factor authentication, encryption, cloud servers, de-identification, etc.)? What policies are in place to mitigate security threats?

	P.1.2 Build Trust in Data Systems	Align with best data protection and privacy practices for storage of data (e.g., two- factor authentication, encryption, de-identification)	What measures do you take to ensure the security of the patients' collected data (two-factor authentication, encryption, cloud servers, de-identification, etc.)? What policies are in place to mitigate security threats?
	P.1.3 Ensure Data Security	Mitigate risks related to security threats through safe storage guidelines for confidential data	
		Consider federated data systems (federated storage) across the health system	
P.2. Promote Health Value	P.2.2 Promote Data Sharing & Interoperability	Support multi-sector partnerships	
P.3. Prioritise Equity	P.3.2 Establish Data Rights & Ownerships	Develop health data trusts and health data cooperatives to define rules of data storage	How familiar are you with local data governance laws and regulations (your setting, the country)? What do you know about them?
			In your opinion, what are the main principles/ pillars of data governance in healthcare? (need to give probing questions here if they are not aware of them: protect people, promote health, and prioritize equity)
			What is the importance or goal of data governance in healthcare, and how could it be achieved?
DATA SECURITY			
P.1. Protect People	P.1.1 Protect Individuals & Communities	Use secure data storage mechanisms (e.g., encryption, cloud servers)	How and where do you store your patients' data (onsite computers, online servers, file archives, etc.)?
			What measures do you take to ensure the security of the patients' collected data (two-factor authentication, encryption, cloud servers, de-identification, etc.)? What policies are in place to mitigate security threats?
	P.1.2 Build Trust in Data Systems	Align with best data protection and privacy practices for storage of data (e.g., two- factor authentication, encryption, de-identification)	What measures do you take to ensure the security of the patients' collected data (two-factor authentication, encryption, cloud servers, de-identification, etc.)? What policies are in place to mitigate security threats?
	P.1.3 Ensure Data Security	Require strong technical security measures for data processing (data security audits)	What measures, if any, are taken to validate the quality and accuracy of the collected and stored data? Are you responsible for quality check? If not, who is?

		Mitigate risks related to security threats	What measures do you take to ensure the security of the patients' collected data (two-factor authentication, encryption, cloud servers, de-identification, etc.)? What policies are in place to mitigate security threats?
		Enhance data security through federated data systems	
		Apply a human rights lens to health data governance (both traditional rights, e.g., security, health and new rights associated with data, e.g., privacy)	

MENA OBSERVATORY
ON RESPONSIBLE AI
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Governing Responsible Artificial Intelligence and Data
in the Middle East and North Africa (MENA)

The American University in Cairo
Onsi Sawiris School of Business
Access to Knowledge for Development Center

IDRC · CRDI
International Development Research Centre
Centre de recherches pour le développement international

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