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

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Enhancing Patient Data Governance in Tunisia: Addressing Challenges and Fostering AI Innovation in Healthcare

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ENHANCING PATIENT DATA GOVERNANCE IN TUNISIA: ADDRESSING CHALLENGES AND FOSTERING AI INNOVATION IN HEALTHCARE

Policy Brief

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I. KEY MESSAGES TO POLICY MAKERS

Tunisia should pay particular attention to issues related to patient data governance by developing an ethical data ecosystem that addresses healthcare challenges and facilitates the adoption of technological advances, such as artificial intelligence (AI).

II. BACKGROUND TO THE POLICY BRIEF

This policy brief contributes to the discussion on health data governance and artificial intelligence in the MENA region, with a focus on Tunisian patient data. It integrates research findings and context-specific insights from a research study addressing patient data usage in Tunisia by incorporating results from a questionnaire administered to healthcare professionals, complemented by semi-structured interviews. This approach provides a comprehensive understanding of Tunisian patient data governance, synthesizing and contextualizing the challenges and potential solutions.

III. THE PROBLEM

Tunisia, like many countries in the MENA region, faces significant challenges in the governance of data within the healthcare sector.[1] This issue is of great importance in the context of modernizing Tunisia's healthcare system to fully exploit the potential of new technologies, such as the integration of artificial intelligence.[2]

More specifically, patient data are essential resources for supporting medical innovation, developing new treatments, and enhancing healthcare quality and accessibility.[3] However, given the importance and immense potential of this data, there are legitimate concerns about its use. In this regard, it is crucial to strike a delicate balance between harnessing the benefits of this data and ensuring robust safeguards are in place to protect patients' personal information.[4]

IV. SIZE OF THE PROBLEM

Healthcare institutions collect a significant amount of patient information. However, this data is often incomplete and difficult to access and utilize. The importance of improving patient data governance is frequently overshadowed by the urgent challenges facing public health institutions. The primary challenges in healthcare stem from the significant disparities in digitization levels among healthcare entities, coupled with the fragmentation and heterogeneity of information systems across public healthcare establishments.[5] As a result, this disrupts the coordination and continuity[6] of healthcare, reduces the efficiency of healthcare facilities, and hinders the advancement of medical research[7] and innovation projects that rely on data and adopting AI techniques.

V. UNDERLYING FACTORS

Financial and Socioeconomic Constraints: Financial constraints are a major obstacle, impacting both the ability to promptly and adequately respond to technological infrastructure requirements and the ability to attract and retain highly qualified medical[8] and technical personnel. Many qualified and skilled professionals choose to pursue career opportunities abroad to benefit from better working conditions and higher salaries.

Awareness and education: There is a significant lack of awareness among stakehold-

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[1] Michelle Li, Isabel Brodsky, and Eric Geers. Barriers to Use of Health Data in Low- and MiddleIncome Countries. MEASURE Evaluation, Palladium. https://www.measureevaluation.org/resources/publications/wp-18-211/at_download/document.

[2] Wahl, Brian, Aline Cossy-Gantner, Stefan Germann, and Nina R Schwalbe. 2018. "Artificial Intelligence (AI) and Global Health: How Can AI Contribute to Health in Resource-Poor Settings?" BMJ Global Health. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6135465/

[3] Adane, Kasaw, Mucheye Gizachew, and Semalegne Kendie. 2019. "The Role of Medical Data in Efficient Patient Care Delivery: A Review." Risk Management and Healthcare Policy. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6486797/

[4] Kaplan, Bonnie. 2016. "How Should Health Data Be Used?: Privacy, Secondary Use, and Big Data Sales." Cambridge Quarterly of Healthcare Ethics https://www.cambridge.org/core/journals/cambridge-quarterly-of-healthcare-ethics/article/abs/how-should-health-data-be-used/D3762C502A4C38EA79F1B516AD3665D2

[5] "Programme de Développement de La «Santé Numérique» En Tunisie - Ministère de La Santé Publique." http://www.santetunisie.rns.tn/fr/prestations/programme-de-d%C3%A9veloppement-de-la-%C2%ABsant%C3%A9-num%C3%A9rique%C2%BB-en-tunisie

[6] Chiolero, A., Calbimonte, J.-P., Manzo, G., Alves, B., Schumacher, M., Gaillard, S., Schaller, P., & Santschi, V. (2021). Exploiter les données du dossier médical informatisé pour améliorer la qualité des soins en ambulatoire. Revue Médicale Suisse, 17, 2056-2059. https://www.philippe-schaller.ch/assets/img/presse/2056-9_42792.pdf

[7] Nordo, Amy Harris, Hugh P. Levaux, Lauren B. Becnel, Jose Galvez, Prasanna Rao, Komathi Stem, Era Prakash, and Rebecca Daniels Kush. 2019. "Use of EHRs Data for Clinical Research: Historical Progress and Current Applications." Learning Health Systems. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6508843/

[8] Sami Ghorbal. 2017. "Tunisie : le grand exode des médecins - Jeune Afrique.com." JeuneAfrique.com. https://www.jeuneafrique.com/mag/392696/societe/tunisie-grand-exode-medecins/

ers[9] regarding the medical, ethical, and innovative challenges associated with data and the requirements of future AI adoption. As a result, they are less likely to address these critical issues.

Governance: In 2018, the INPDP[10] issued Deliberation Number 5, which consists of 35 articles that define standards for health data protection. Despite the fact that this regulation is essential for ensuring the security and confidentiality of patient data, it is not sufficient to ensure effective and ethical data governance across the different levels of processes that shape patient data use.

VI. RESEARCH TAKEAWAYS

The Electronic Medical Record (EMR) plays a crucial role in establishing and organizing patient data governance in terms of collection, sharing, storage, and security. It represents a solution to the challenges associated with using paper medical records. These difficulties often include poor readability of handwritten notes, a notable lack of detail in documentation, risk of document loss, and the complexity of regulating access to records. These issues are particularly problematic during the transfer of medical follow-up between healthcare professionals, especially for patients with chronic diseases.

However, transitioning from paper to digital records presents significant challenges[11], requiring substantial organizational transformation. This shift involves not only adopting new digital tools but also altering established habits, which often leads to considerable resistance. Ensuring healthcare professionals' engagement in responsible and effective use of these tools is a complex task that requires careful planning and support.[12]

The use of multiple medical records across different services and healthcare establishments leads to data dispersion and undermines the comprehensiveness of patient data. Using a single EMR per establishment, as seen in private clinics, helps address this issue by integrating and communicating subsystems within the patient's care pathway. Achieving this interconnection, known as interoperability, is central to the evolution and optimization of the EMR. This feature improves coordination between healthcare professionals involved in patient care by facilitating data exchange, with access levels tailored to the specific needs of care, thereby respecting patient confidentiality. This collaboration represents an opportunity for the future adoption of AI in the health sector.

As health assessment, research, and technological innovation projects are developed, challenges related to patient data governance become increasingly evident. In particular, this applies to the processing and sharing[13] of data. There is a difficulty in obtaining comprehensive and large samples of data due to persistent reluctance to share[14] medical data, even among healthcare professionals. In addition to this, data from a variety of sources is often scattered and challenging to exploit, making it complex and expensive to process. Due to these obstacles, it is difficult to develop innovative projects based on data processing especially those using artificial intelligence[15], which requires the collection of thousands of patient data sets to establish correlations and provide predictions.

Despite these challenges, we can observe the development of initiatives based on image processing for analysis and diagnosis. One notable example is the "InnoDeep"[16] platform, which combines teleradiology with artificial intelligence to provide an effective and timely response to diagnostic and therapeutic needs. This solution was adopted by public health establishments during the COVID-19 pandemic, demonstrating the potential of such technologies in healthcare.

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[9] Pappaioanou, Marguerite, Michael Malison, Karen Wilkins, Bradley Otto, Richard A Goodman, R. Elliott Churchill, Mark White, and Stephen B Thacker. 2003. "Strengthening Capacity in Developing Countries for Evidence-Based Public Health:: The Data for Decision-Making Project." Social Science & Medicine. https://www.sciencedirect.com/science/article/abs/pii/S0277953603000583?via%3Dihub.

[10] INPDP. Recueil de la Protection Des Données Personnelles (2021).https://inpdp.tn/Receuil_INPDP.pdf

[11] Boonstra, Albert, and Manda Broekhuis. 2010. "Barriers to the Acceptance of Electronic Medical Records by Physicians from Systematic Review to Taxonomy and Interventions." BMC health services research. https://pubmed.ncbi.nlm.nih.gov/20691097/

[12] Ben Hammouda, Seif, and Slim Hadoussa. 2018. "Projet e-santé Tunisie : étude des facteurs d'acceptation du Dossier Médical Informatisé (DMI) par les médecins auprès des hôpitaux." Management & Avenir. https://www.cairn.info/revue-management-et-avenir-2018-4-page-15.htm

[13] Bull, Susan, Nia Roberts, and Michael Parker. 2015. "Views of Ethical Best Practices in Sharing Individual-Level Data From Medical and Public Health Research." Journal of Empirical Research on Human Research Ethics 10(3): 225–38. doi:10.1177/1556264615594767.

[14] van Panhuis, Willem G, Proma Paul, Claudia Emerson, John Grefenstette, Richard Wilder, Abraham J Herbst, David Heymann, and Donald S Burke. 2014. "A Systematic Review of Barriers to Data Sharing in Public Health." BMC Public Health. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4239377/

[15] Wahl, Brian, Aline Cossy-Gantner, Stefan Germann, and Nina R Schwalbe. 2018. "Artificial Intelligence (AI) and Global Health: How Can AI Contribute to Health in Resource-Poor Settings?" BMJ Global Health. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6135465/

[16] Docteur Imago. (2023, 11 septembre). La téléimagerie combinée à l'IA permet de gagner du temps sur le diagnostic. https://docteurimago.fr/actualite/produits/la-teleimagerie-combinee-a-lia-permet-de-gagner-du-temps-sur-le-diagnostic/

VII. POLICY RECOMMENDATIONS

Enhancing digital proficiency in the healthcare sector: The healthcare sector needs to establish targeted training programs for current staff. Moreover, mandatory modules tailored to the profiles of future healthcare professionals should be integrated into university curricula. These programs should include content designed to raise awareness of data governance and artificial intelligence and their ethical and medical implications.

Establish a Reference Body for Patient Data Governance: The principal objective of this entity is to develop and maintain a robust, effective, and ethical health data governance framework. It should have the necessary skills and authority to facilitate collaboration among various stakeholders involved in patient data operations and to ensure compliance with international best practices, such as the “Principles of Health Data Governance”.[17] This well-structured health data governance framework will ensure that the data is high-quality, accessible, ethically managed, and compliant with legal standards, which will allow AI technologies to be deployed effectively, leading to better health outcomes.

VIII. IMPLEMENTATIONS CONSIDERATIONS: BARRIERS & COUNTERSTRATEGIES

In many healthcare institutions, data governance is not prioritized, and budget constraints in the public health sector further hinder the widespread implementation of electronic medical records (EMRs) that may lay the groundwork for successful AI integration. It is also challenging to engage healthcare professionals in the effective and responsible use of EMRs and the digitalisation of the healthcare sector. Additionally, the variety of information systems in use complicates efforts to ensure data interoperability between healthcare facilities. These issues hinder the development of a data ecosystem favorable to innovation, particularly that involves artificial intelligence, which requires large amounts of high-quality data that are difficult to obtain.

IX. NEXT STEPS

To advance AI-driven medical research and innovation projects in Tunisia, it is crucial to emphasize the need for responsible and ethical medical data governance in this domain. Without significant improvements in data governance and infrastructure, the potential for AI adoption in healthcare will be limited. However, if these challenges are effectively addressed, Tunisia could pave the way for substantial advancements in AI applications, leading to improved patient care and medical innovation.

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[17] Health Data Governance. Strengthening health data governance in the digital age. http://healthdataprinciples.org/

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