

# Governance guidance for an eRegistry for maternal and child health: Lessons from the occupied Palestinian territory

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## Abstract

**Background:** The eRegistry for maternal and child health is an electronic registry system developed for the collection, analysis, retrieval, storage, and dissemination of information on health determinants and outcomes for women and children with the purpose of improving health care provision and public health surveillance in the occupied Palestinian territory (oPT). Given the highly sensitive nature of reproductive health information, however, careful attention to ethical and legal considerations is essential. Mapping the legal, regulatory, and ethical landscape using a situation analysis tool tailored for the Palestinian context was undertaken in order to identify gaps, opportunities, and actions necessary to ensure an ethical and lawful framework for an eRegistry.

**Methods:** This research utilized an exploratory situation analysis tool (SAT) in the oPT to map the current legislative, regulatory and governance environment. The primary objective was to assess, document, and analyze the legal and ethical landscape in the oPT. Specific focal topics addressed by the SAT include identifying relevant legislation (i.e., civil registration, data privacy, health registries, public health law, etc.), existing governance structures, accountability, and oversight bodies (i.e., ethical review committees, data protection authorities), and data quality and security policies. The Palestinian National Institute of Public Health (PNIPH) completed the SAT and conducted workshops with relevant stakeholders including the Ministry of Health's Legal Affairs department, PNIPH staff, and other legal experts. Given that data collection consisted of public documents, no ethical approval was required.

**Findings:** The findings from the SAT reflect the oPT's current situation with respect to existing laws, accountability and oversight bodies, and data collection protocols and policies concerning data privacy and security. Existing Palestinian legislation relevant to health registries includes Article 4 of the General Statistics Law (2000) that honors data confidentiality and individuals' privacy. The Penal Law No. 16 of 1960 addresses the disclosure of confidential information while Article 355 specifically states that anyone disclosing official confidential information to unauthorized persons is unlawful and may result in imprisonment. In addition, the Public Health Law (2004) addresses general maternal and child health issues in Articles 4 and 5. The SAT investigated relevant oversight and accountability bodies (e.g., ethical review board) that may be relevant to an electronic maternal and child health registry. Finally, a review of existing data privacy protocols and policies noted that few formal protocols (i.e., privacy manual) or policies regulate data collection and access practices.

**Interpretation:** The findings gathered using the SAT pinpoint specific areas within the oPT's legal and regulatory framework that may be strengthened. The eRegistry Governance Guidance Toolkit (GGT), predicated on the SAT content, outlines responsible data stewardship practices and provides assistance in developing protocols and policies in lieu of specific existing laws by providing a framework to ensure the protection of women and children's privacy. Developing effective governance that protects women and children's privacy and confidentiality is essential for maintaining public trust and ensuring the long-term success of a registry.

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**Contributors:** SM developed the SAT and contributed to analysis, writing and revisions. In the oPT, BG and RS orchestrated mapping and data collection and contributed to the analysis and writing. JK's legal expertise informed the overall design and data collection strategy. All authors contributed to the writing and editing the final version.

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