



eRegistries
Initiative

learning package

introduction

core principles

Effective health interventions are driven by evidence and data, but a lack of maternal health data, particularly in low-income settings, has impeded global efforts to reduce maternal mortality and improve health outcomes at birth. The existing systems for capturing maternal health data are often old, cumbersome and inefficient, or newly digitized, but siloed, single purpose or small in scale. Data are often never reported or analyzed at the program level, nor are they systematically used to improve individual patient care.

The eRegistries concept sees women as more than data points, and care providers as more than data collectors. It combines point-of-care data collection with clinical decision support and traditional health registries, resulting in single data entry that is used for improved patient care, supervision, program management, decision making at all levels, and research. **It is founded on the following principles:**

- **Continuity of care requires continuity of data**
- **Quality of care is enhanced by clinical support tools**
- **Health information systems should never serve a single user group, but should support patients, care providers, program managers, and global monitoring alike**
- **Open, integrated and adaptable systems are necessary for sustainability and scalability**
- **Strengthening research efforts, and documenting and publishing findings magnifies impact**

These principles build on the *MA4Health Roadmap*, the *Principles for Digital Development*, and the *Global Strategy for Women's, Children's and Adolescents' Health*.

The eRegistries approach reduces the reporting burden, improves guideline adherence, promotes continuity and quality of care, improves data quality, increases visibility of health behaviors and trends, and reduces the reliance on expensive surveys and stand-alone data collection activities to collect clinical data.

The *eRegistries Initiative* is supported by global donors and country partners, and is housed at the Norwegian Institute of Public Health. It provides a framework, tools and resources for creating, implementing and evaluating electronic health registries based on globally accepted standards, research and implementation experience. The framework addresses critical issues including legal and ethical concerns, software considerations, evidence-based indicator selection, training, knowledge transfer and dissemination strategies that pertain to maternal and child health. They are written by and for international development donors, multilateral organizations, and implementing partners, and are made freely available online. The eRegistries Initiative collaborates with partners globally to provide training and technical assistance to establish, build and manage high quality electronic health registries.

Our vision is a world in which health data is collected safely, systematically, and routinely and used effectively and efficiently to achieve the highest quality of health and well-being for women and children around the world.

Our mission is to strengthen the global capacity to systematically improve data quality and use by providing tools that support ethical, safe, legal, culturally appropriate, and efficient health registries that focus on maternal and child health.

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introduction to eRegistries

This brief introduction to eRegistries will facilitate the understanding of what are registries, how they work and whether they may be a good solution for the information needs in your setting.

WHAT IS AN EREGISTRY?

The electronic registries developed and supported by the partners of the eRegistries Initiative are **public health information systems**. They are designed specifically to serve the information needs for health systems aimed at implementing the actions and achieving the goals of the United Nation's Global Strategy for Women's, Children's and Adolescent Health.

At its core, eRegistries hopes to **secure an infrastructure for health information** which supports universal health coverage with continuity of care, quality content of care, monitoring of care provision and health outcomes, and high quality data which reports on key indicators of performance. Whether using a small or comprehensive health program, this core information requirement remains the same.

The eRegistries similarly supports the visions of the WHO/World Bank/USAID Monitoring and Accountability for Health initiative (now embedded in the United Nation's Health Data Collaborative), arguing that "Public health and clinical care cannot be delivered safely, with high quality, and in a cost-effective manner, without seamless, sustainable, and secure data and information exchanges at all levels of the health system". eRegistries therefore continuously collects and uses health information on individual clients or patients (see definition below), securely retains the information in a centralized server as a continuity of their individual health

and care, and makes the information available across all levels of the health system. This is the only way health information can be managed as one single “backbone” system in order to support the variety of information needs from individuals, their care providers, and those managing health care systems and programs.

eRegistries does not provide complete electronic medical record systems intended for all aspects of highly specialized hospital care for women and children. eRegistries relies upon the systematic collection of uniform data, and the well-defined essential interventions, care algorithms, targets and indicators for women’s and children’s health of the UN Global Strategy which makes such health programs especially suitable for the methodology of eRegistries.

eRegistries are designed as an all-purpose backbone health information system where information is collected just once, in a continuous and prospective manner. As a result, it also serves multiple innovations in mHealth, reduces the work load of reporting for the health work force, and creates invaluable data resources for research in women’s and children’s health.

eRegistries are systems using information and communication technologies for the systematic longitudinal collection, storage, retrieval, analysis, and dissemination, of uniform information on health determinants and outcomes of individual persons, to serve healthcare services, health surveillance, health education, knowledge, and research. Adapted from [ref. 1-3]

HOW DOES AN EREGISTRY WORK?

eRegistries are always designed with the users to meet their local needs, and will, therefore, have various specifications and functionalities in these different settings. Some core principles do apply to how partners in the eRegistries Initiative work in developing a functional eRegistry, including:

- eRegistries are **governed legally and ethically** by securing ethical use of information, maintaining individuals’ privacy, and openness and accountability towards the communities they serve.

- eRegistries **offer a global common good**, and therefore, are implemented in free, adaptable, integrated, scalable and sustainable open software systems where advances and improvements are openly shared in the community.
- eRegistries **work with and within health systems** – health information systems must be integrated in the work flow of the system, and not as an isolated “add-on” system that only increases the work load to register data.
- eRegistries are not developed in a silo to serve a single user group, but are **designed to support the information needs of patients, care providers, program managers, and global monitoring entities** alike. Conversely, unused data should not be collected.
- eRegistries are **designed with the users** across the health system for real-time continuity of useful health information within the continuity of care. As a result, the registry’s data reflects evidence-based interventions for women and children, and provides validated and internationally harmonized indicators reflecting the quality and outcomes of health promotion and care.
- Entering data into an eRegistry **benefits the care provider and the quality of care provided** to their clients and patients. This is typically used as point-of-care data collection through a user interface that provides functionalities such as check-lists of care provision, interactive clinical decision support tools, automated reminders, referrals or other supportive tools that assists the provider in their work.
- The development, implementation and operations of **eRegistries should be documented, monitored and subjected to research** in order to strengthen the knowledge-base of public health registries as a common good for women’s and children’s health.

Within such a setting, an eRegistry would typically work as an electronic work-aid for the care provider and carried on

any tool ranging from a mobile phone to a desk-top computer. When identifying and securely logging in, the care provider would have a full overview of the scheduled clients of the day. Interactive forms serving as check-lists with clinical decision support would not only provide the basic documentation of individual health assessments and care provision, but assist the provider in adhering to guidelines of care based on the information entered.

The data would be uploaded real-time or stored locally until internet access is available for upload, making the information available to all levels of the care system that the woman or child might need to access for her continuity of care, and also generate automated referrals to the appropriate level.

Simultaneously, anonymous data from the eRegistry, transformed from care-appropriate data to validated indicators displayed in graphical or tabular dashboards, would be made available at aggregated levels for supervision, monitoring and reporting; thereby, relieving the care provider from any reporting work-load. The eRegistry can further support a variety of mHealth applications targeting all levels of users through web-applications or mobile networks.

HOW CAN IT BENEFIT YOU?

Depending on the design of an eRegistry, some typical potential advantages over paper-based, multiple, or non-registry based health information systems can include:

- **Saving time and resources** in the work force through more efficient data collection via one single, all-purpose health information system with one single data entry.
- **Better quality of the data with validation** of data entry in electronic forms addressing the accuracy, uniformity and completeness, and unbiased assessments of programs through prospective collection of health determinants and care provision prior to (adverse) outcomes.
- **Better use and availability of data** to support continuity

of care with seamless, real-time health information across providers to prevent duplication of work and support efficient hand-offs, referrals and discharge

- **Better use of data to support universal coverage** of essential interventions and the quality of care through interactive data entry forms with clinical decision support, rule-based workflow and care algorithms.
- **Uniform data providing comparability** across settings and countries corresponding to validated indicators of quality of care for evidence-based essential interventions, well-defined health outcomes according to WHO and ICD standards, and registration of vital events.
- **Full flexibility for aggregation or disaggregation** for use ranging from nationally aggregated data for supervision of health systems performance or public accountability, to automated individualized feedback on performance to a single clinic or care provider, to customized reminders or health information messaging to an individual woman's mobile phone.
- **A functional backbone database** of both individual clients and individual care providers to drive multiple mHealth applications in support of RMNCH, from human resource management to supply chains or vital event tracking as referenced in article, *eRegistries: Electronic Registries for Maternal and Child Health*
- **Facilitation of ethical and legal governance** of privacy and security of health information in one single system which is encrypted and secured using widely accepted standards such as HL7.
- **Free open source software** systems with support from world-wide developer groups, and eRegistry partners.
- **A health information system** designed to the support of the *MA4Health Roadmap*, the *Principles for Digital Development*, and the *Global Strategy for Women's, Children's and Adolescents' Health*.

REFERENCES

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