

# An Informatics Framework for Maternal and Child Health (MCH) Monitoring

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**Abstract.** Most cases of maternal deaths could be avoided with timely access to quality healthcare, but a key challenge in addressing quality of care in maternal health, is the lack of accurate data. We present a review of the difficulties of collecting and analyzing maternal health data. We propose a comprehensive informatics monitoring framework to track progress on the achievement of the international targets and priorities toward ending preventable maternal mortality and improving maternal and child health, that at the same time builds capacity at institutional and country level to collect indicators and to generate actionable and comparable knowledge that facilitates analysis, research, and evidence-based decision making.

**Keywords.** Health information technology (HIT), maternal, child

## 1. Introduction

According to a 2016 systematic analysis by the United Nations (UN), approximately 830 women die every day around the world from preventable causes related to pregnancy, and 99% of all maternal deaths occur in low- and middle-income countries (LMICs) [1]. A large and growing body of research suggests that most cases of maternal deaths could be avoided with timely access to quality healthcare [2]. A key challenge in addressing quality of care in maternal health, is the lack of accurate data. For example, in many low-income countries, maternal deaths go uncounted and frequently the cause of death is unknown or not recorded correctly and the maternal care process is equally poorly registered or not registered at all [3]. Many patient registration systems and electronic health records in low resource settings have problems with non-standardized record-keeping techniques which result in missing records, inconsistencies, poor data quality, and inaccuracies and hence undermine evidence-based decision making in healthcare service delivery [4]. This makes it difficult for national health programs to allocate resources where they are needed the most. To achieve this goal is necessary the integration and harmonization of high amounts of heterogeneous medical data that is stored in different health information systems. Such a task is challenging in both developed [5] and developing countries [6]. In this paper, we review some of the challenges in collecting and analyzing this data, and we propose an ontology-based data integration approach to effectively combine data from heterogeneous sources.

## 2. Current Approaches

Comprehensive database applications for a domain can reduce variation within that domain. There are some proposals such as the Perinatal Information System (SIP) developed by the Pan American Health Organization (PAHO/WHO/CLAP). SIP's aim is for the health team to learn about the characteristics of the health service users, assess the outcomes of the care provided, identify the priority problems and conduct a operational studies [7]. It contains a model of perinatal clinical history with pre-codified and open data, 170 variables entered by clinicians or under their supervision. SIP has been modified several times due to the need to keep their contents updated, as well as to include the priorities - national and international - defined by the Ministries of Health of the region. It also allows automated report production and the transferring of local data across institutions. The tutorial handbook contributes to the record's consistency. In a study [8] in 20 maternity hospitals (5 Countries, 40% Private and 60% Public) 85% had a reliable information system by the third year of use of SIP. 15% of hospitals still had problems at that time that were already clear during the second year. The evaluation of the impact of yearly reports shows that 58% of recommendations were fulfilled, especially those regarding the complete filling-in of clinical records (62%) and to a lesser extent, variables that reflect clinical practices and organization of services (52%).

One of the most comprehensive and proven perinatal datasets is the one implemented at the Medical University of South Carolina (MUSC) Perinatal Information System (PINS). A validated, research-quality perinatal database with multiple edits and audits to ensure accuracy [9], for all women delivering at the MUSC, which is a regional tertiary referral hospital in the southeastern United States. The MUSC PINS database includes detailed information on each mother's medical history, linked to neonatal data (such as medical diagnoses, medications, and laboratory tests) from delivery to hospital discharge. However, even though it is a statewide regional perinatal information system, comprehensive antenatal care information from outside the hospital setting is not available.

The Netherlands established national domain information models to support electronic information exchange based on HL7 RIM, using cases from perinatology as a national pilot, with the aim to support the development, adoption, implementation, and maintenance of the EHR in Dutch healthcare practice [10]. They chose perinatology because there was an existing need for communication improvement with a sufficient consensus and standardization among different professionals represented in a national data set. Their approach was to allow clinicians to understand better where 'their' information is in the Domain Message Information Model (D-MIM) to individually analyze each information item, attribute and value in the domain and map it to existing HL7 RIM classes, attributes, and vocabularies. They found that in some instances, additional agreements are necessary about the preferred vocabulary in the Netherlands, because the professional organizations need to harmonize their materials. Another finding was that the limitations are reached for what should be part of the (national) standard, and what professional organizations should develop and maintain within their realm.

The Global Network Maternal Newborn Health Registry (MNHR) provides prospectively collected, population-based pregnancy outcomes for defined geographic regions within low- and middle-income countries [11]. Its data describes demographic and healthcare characteristics and major outcomes of pregnancy. All definitions used by the MNHR are consistent with the WHO definitions, whenever possible. One of the

limitations of the MNHR is the difficulty in ensuring the inclusion of all pregnancies, and especially those with early pregnancy loss. Some sites encounter challenges in tracking the outcomes of pregnant women who migrate in or out of the study clusters. Other challenges include categorizing critical pregnancy outcomes, determining accurate birth weights of certain groups of infants e.g., stillbirths, infants delivered at home. The MNHR also is a tool for evaluating the effectiveness of strategies of care because, unlike with the use of periodic surveys, data is collected continuously over time within the same population-based cohort. This enables investigators to determine the impact of interventions to improve outcomes, to monitor trends over time, and to evaluate the changing patterns of perinatal care to inform health policy.

### **3. Current Issues**

Regarding the consensus on data indicators, some issues persist. For example, despite the global burden of perinatal deaths, there is currently no single, globally acceptable classification system for perinatal deaths. Instead, multiple, disparate systems are in use worldwide. The World Health Organization (WHO) is developing a globally acceptable classification approach for perinatal deaths [12] but these have not been universally adopted. While the integrated WHO tool is designed to assess quality across the continuum of care, the standards currently included in the tool are not fully representative of all the areas of care that need to be assessed. Antenatal care is not assessed at all and postnatal care in a very limited way. These are typically neglected areas of care that are often not included in quality improvement activities. This is in part because national standards for antenatal and postnatal care are often not in place. Developing such standards and including them in a comprehensive quality of care assessment is a priority.

The inter-country differences in registration systems, also imply biases in recorded mortality rates. The challenge is to distinguish ‘real’ variations in the value of an indicator from variations due to differences in registration practices and definitions and from random variation [5]. From a practical point of view, a compromise must be struck between useful, important indicators that satisfy many of the formal characteristics and are still accessible. Mortality indicators are particularly sensitive to biases related to the construction of indicators. For example, changes in birth notification and registration practices can cause major biases. In 1994 Germany reduced the lower limit for birth weight for registration of fetal deaths from 1000 to 500 g. Consequently, the perinatal mortality rate jumped suddenly from 5.5 per 1000 to 6.6 per 1000, an increase of 20% [13].

Databases using the International Statistical Classification of Diseases and Related Health Problems (ICD) can facilitate cross-country comparisons, but revisions can alter the results of comparisons. Regarding perinatology, in its 10<sup>th</sup> revision, chapters ‘‘O’’, ‘‘P’’ and ‘‘Q’’ are relevant to perinatology. An analysis of these codes shows that 163 ICD9 codes are mapped onto 235 ICD10 codes in chapter P, and 180 ICD9 codes for anomalies onto 620 ICD10 codes [14]. Changes in the ICD version used to register causes of death or morbidity will consequently result in systematic shifts in the overall levels reported. The World Health Organization (WHO) and collaborating partners are developing the WHO Application of ICD-10 to perinatal deaths: ICD-Perinatal Mortality (ICD-PM) [12]. Tables comparing causes of death and morbidity across countries should explicitly state the ICD version used for coding.

Some countries have taken steps to homogeneous coding practices on a national level. For instance, the Danish society of gynecology and obstetrics has elaborated a guideline for registration of births which selects a number of codes from ICD10 and the Nordic Classification of Surgical procedures and Treatments that were found to be relevant for registration on a national level, with additional definitions and criteria for use where necessary [15]. In general, the burden on individual providers of collecting data has been well documented [16], as has the lack of use of data collected at such great cost [17], which breaks the feedback mechanism whereby monitoring and review can result in improved provision of interventions.

Another challenge is data aggregation and overlap. For maternal care, clinical data is often generated from various sources (prenatal screenings, primary care providers, midwives) and the health information may exist in both paper-based and computer-based systems at institutions located in different geographical locations. The overlap across systems introduces the potential for data variation through duplication of data entry and differing concept definition or context of use. Studies show that redundant and inconsistent records lead to errors, extra effort, misdirected data, over-reliance on the spoken word, inaccuracies, information loss, limited standardization, miscommunications, decision changes, and limited outcomes evaluations [18]. Also, failure to share patient information across data systems can lead to inefficiency and reduce the quality of care. One study [19] pointed out the deficiency in communication among health professionals and that both lack of communication and lack of clarity of medical records are major causes of medical incidents. Research has shown how coordination and communication among clinicians and across settings resulted in greater efficiency and better clinical outcomes [20]. An Institute of Medicine report [21] explained that a health system must have efficient and accurate ways of capturing, managing, and analyzing clinical data collected at all the different sites where care is provided.

Also, the course of pregnancy, childbirth and child development involves a series of stages referred to as the prenatal, intrapartum and postnatal periods of care, involving several medical disciplines during each stage, using a variety of technical jargon registered in different systems. The ability of communication among EHRs that contain such kind of information, which would allow interoperability, requires that terms in all involved systems share their semantics. However, gathering information from EHRs connected to different information systems is a challenge and involves the adoption of semantic interoperability solutions. To address this, the healthcare sector has developed standards for medical vocabulary (SNOMED-CT) and message information models (FHIR) that carry many of the features present in Semantic Web standards such as the Web Ontology Language (OWL). For example, Implementing FHIR in MCH domain, requires additional structure definitions and rules about which resource elements and terminologies map to particular MCH requirements [22]. Semantic interoperability is then also needed because of the seemingly arbitrary meaning of data across different health sectors, which may result to classification errors when collecting data. The solutions based on formal ontologies can enable the effective semantic interoperability because for systems to interoperate, they have to share the meaning of their terms, which requires a well-defined semantics.

Obstetric and Neonatal Ontology (OntONeo) [23], aims to represent the diversity of data registered in EHRs involved in pregnancy care. Such ontology will be able to join different standards and terminologies adopted by information systems that deal with prenatal EHRs and provides a demanded specialized vocabulary planned to include a

more comprehensive formal representation in comparison with other currently available ontologies and terminological resources. OntoNeo still needs additional validation in different communities of physicians and healthcare professionals.

#### 4. Towards a Comprehensive Framework for Maternal Health Informatics

The still high maternal mortality ratio (MMR) could be explained because gains in coverage do not always result in safe and high-quality obstetric care due to limitations of *training and process improvements*. To achieve sustained improvements, local groups will need not only need outcomes metrics and education on best practices for care but also to develop ways to examine their current care delivery process and identify areas for improvement: ‘What gets measured gets managed’ [24]. Studies have also shown that medical knowledge, job satisfaction, and self-efficacy do not increase by only using continuing medical education (CME) intervention and that using only one mode of learning fails to stimulate lateral learning i.e. learning from your peers [25]. We are currently developing a comprehensive set of metrics for maternal outcomes and process variables that will be useful for low- and middle-income countries. An Alicanto™ (<http://www.alicantocloud.com>) social community education site is being established for maternal health centers in Latin America to have access to evidence-based education and best practices to collect outcomes through the continuum of care, keeping standardization of clinical structure and content across all databases; while being technologically and culturally appropriate. Based on our review of other maternal health databases, an initial set of consensus metrics will be used to track outcomes. An online asynchronous discussion forum will be used for communities of practice to share their experiences and discuss challenges in care delivery and data collection with colleagues. Through the community site, we will provide support and tools on how to collect and analyze that data for quality and process improvement, but we believe that a co-creating approach to developing metrics, is more successful, engageable and sustainable. Of particular interest is what process-oriented data can be collected to measure quality of care delivery in low resource settings.

#### 5. Conclusions

There is a global need to end preventable maternal deaths and to improve maternal and child health. Despite multiple approaches, there is no universal consensus on their implementation, causing discrepant data indicators, heterogeneous coding practices, and data overlap. There are also difficulties in technical and semantic interoperability, causing deficiencies in communication among health professionals. As a result, health systems and governments have very limited outcomes evaluations. We propose a comprehensive informatics monitoring framework that will be created based on a consensus community of practice and an ontology-based data integration approach, in which there is not only data collection, but processes variables are included and can be used in a feedback mechanism to improve training and monitoring. This approach will build capacity at institutional and country level to generate actionable and comparable knowledge that facilitates analysis, research, and evidence-based decision making.

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