

A Framework for Neonatal Prematurity Information System Development Based on a Systematic Review on Current Registries: An Original Research

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ABSTRACT

Background: Registries are regarded as a just valuable fount of data on determining neonates suffering prematurity or low birth weight (LBW), ameliorating provided care, and developing studies.

Objective: This study aimed to probe the studies, including premature infants' registries, adapt the needed minimum data set, and provide an offered framework for premature infants' registries.

Material and Methods: For this descriptive study, electronic databases including PubMed, Scopus, Web of Science, ProQuest, and Embase/Medline were searched. In addition, a review of gray literature was undertaken to identify relevant studies in English on current registries and databases. Screening of titles, abstracts, and full texts was conducted independently based on PRISMA guidelines. The basic registry information, scope, registry type, data source, the purpose of the registry, and important variables were extracted and analyzed.

Results: Fifty-six papers were qualified and contained in the process that presented 51 systems and databases linked in prematurity at the popular and government levels in 34 countries from 1963 to 2017. As a central model of the information management system and knowledge management, a prematurity registry framework was offered based on data, information, and knowledge structure.

Conclusion: To the best of our knowledge, this is a comprehensive study that has systematically reviewed prematurity-related registries. Since there are international standards to develop new registries, the proposed framework in this article can be beneficial too. This framework is essential not only to facilitate the prematurity registry design but also to help the collection of high-value clinical data necessary for the acquisition of better clinical knowledge.

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Keyword

Premature Birth, Systematic Review, Registries, Information Systems, Newborn and Neonatal, Computer Systems Development

Introduction

Low birth weight is considered one of the most important indicators of community health and the main cause of infant mortality [1]. About 120 million babies are born worldwide each year that about 25 million of whom are underweight at birth (the proportion is about 50% in some parts of Asia) [2]. Approximately, 32 million low birth weight infants are born in low-income countries, of whom two-

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thirds belong to Asia [3, 4]; the World Health Organization (WHO) has also presented a 10% prevalence of low birth weight in Iran [5]. Due to the importance of the issue, November 17 is named World Prematurity Day to raise awareness in the world [6-8].

Premature birth is caused by several factors, such as premature rupture of the amniotic sac or membrane, maternal infection during pregnancy, and special economic and social conditions, which is the second underlying cause of death in children under 5 years (44%) [8].

In addition to various illnesses and diseases, premature birth leads to the hospitalization of newborns in intensive care units. According to Kramer's studies, 43 potential factors were considered for the birth of premature babies, changing based on the social, economic, and cultural situations in any region [9, 10]. The determination of the factors, the disease, and treatment methods can reduce the morbidity and mortality rate [11].

Information technology is perceived as an important potential panacea for healthcare organizations and institutes to manage and improve healthcare services in the face of increased demand [12, 13]. The registry and information systems aimed to improve the diagnosis process and provide assistance to healthcare professionals through the examination of patients' data [14].

The combination of this information and registry in the medical field is of great importance and it is contemplated as one of the most important infrastructures for promoting health and social development [15, 16]. Thus, the use of registration systems (registries) facilitates activities such as tracking patients' follow-up trends, evaluating the follow-up process, assessing patient care quality, and collecting the necessary data for planning and creating valuable health care systems [12, 17].

The aims of this study were to investigate the existing studies, including premature infants' registries, identify, extract the required minimum data set, and propose a framework

for premature infants' registry.

Material and Methods

Search strategy

This is a descriptive study that has systematically reviewed prematurity-related registries. A protocol adhered to review articles, based on preferred items to report in systematic reviews and meta-analyses (PRISMA) [18]. Five major search engines, including Web of Science, ProQuest, PubMed, Scopus, and Embase were queried, and then the sources of contained publications were explored to distinguish additional applicable gray letters. The search strategy included four categories of keywords: maternal, newborn and neonatal, prematurity, and registry. These keywords should appear in conjunction with the title or abstract of the article. In Table 1, the key points and tactics of the search were represented.

Study selection

Firstly, repetitive articles were recognized and removed using Mendeley desktop software (version 1.19.4 by Mendeley Ltd.), and a handmade modification was used for validation. If a study was reported in more than one publication and presented the same data, it only included the most recent publication. In the next step, the abstract and title of articles were studied according to the inclusion/exclusion criteria. According to the inclusion/exclusion criteria, the summary and caption of the papers were read. Captions and summaries were tested separately with health information management expertise. The Cochrane risk of bias assessment tool (version 15 March 2019) was used to assess the quality of the study. Risk of bias was performed using the risk of bias template on Microsoft excel which is available in an online supplement [19, 20] (Figure 1).

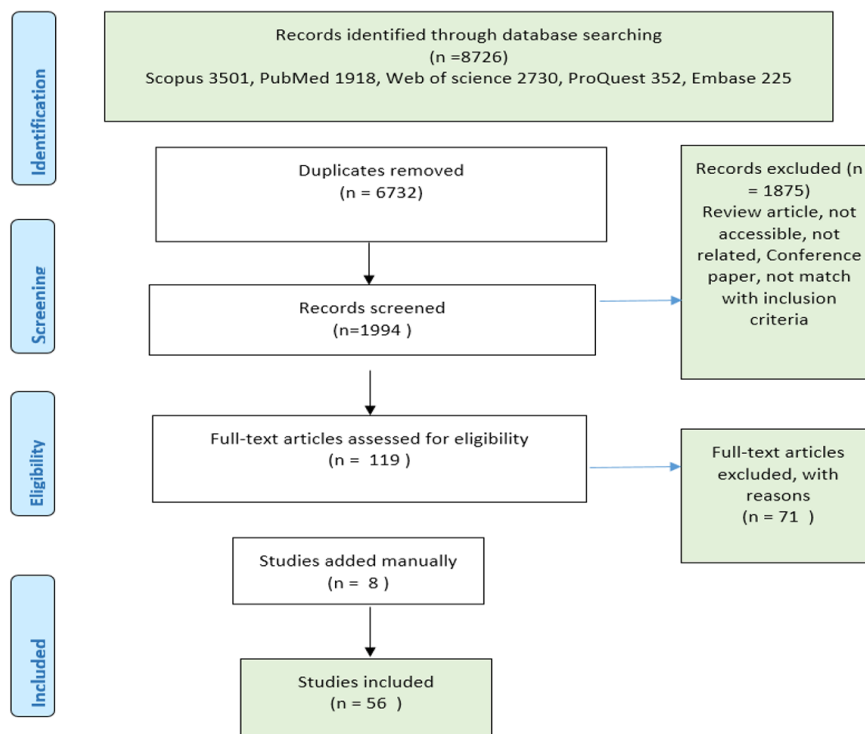
Inclusion criteria

In this review, papers were published as fol-

Table 1: Literature search terms

Item	Category name	Search terms
1	Prematurity	Prematurity, premature, light for gestational age, low birth weight, small for gestational age, SGA, LBW, extremely low birth weight, preterm, preterm birth, preemies, preemies, early birth, preterm delivery, preterm labor.
2	Newborn	Neonatal, neonate, infant or baby, neonate, neonatal.
3	1 and 2	
4	Maternal	Maternal, mother, maternity, pregnancy, pregnant, motherly
5	3 and 4	
6	Registry	Electronic health record, Information system, Dataset, Database, Computerized or Registry.
7	5 and 6	

SGA: Small for Gestational Age, LBW: Low Birth Weight

**Figure 1:** Preferred Reporting Items for Systematic Reviews Flow Diagram (PRISMA) flow diagram.

lows: 1) in English, 2) in full-text (exclude summaries and conference summaries), 3) for neonates, 4) presenting neonates on prematurity or low birth weight, and 5) reported the outcome and registries and databases related to it.

Exclusion criteria

This study aimed to investigate neonates on prematurity and low birth weight, and publishes about not neonates or related to other prenatal diseases, systematic review, review papers, no registry, and none implemented

were excluded.

Data Synthesis

In the current review article, different prematurity registries and databases were reviewed based on a list with the required data elements presented in Table 2. They included the basic registry information (country, registry or database name, acronym, year of establishment, resource maintenance), scope, registry type, and important variables. The validity of the data elements in this list was evaluated by two researchers for extracting data from registries. Based on the articles' aims, only the qualitative data elements from the included registries and databases were extracted.

Results

Overview of Studies

Table 3 includes a summary of the subjects collected during this review in which 8726 papers were recaptured. Overall, there were 6732 duplicates among the databases, which were excluded. After removing duplicates, the abstract and title of 1994 articles were studied concerning the inclusion criteria. At this stage, 1875 articles were excluded, considering the

irrelevance of the article title or abstract. The full texts of 119 articles seemed relevant to the objectives. In the final analysis, 56 articles, considered eligible, were included. Eight articles were found and added through searching the Google Scholar engine manually (Figure 1).

As shown in Table 3, the contained 51 information systems were investigated and described prematurity registries based on the continent, region, registry, name of the system, abbreviation, year of development, scope, registry type, and resource focus.

Among the surveyed systems (51 systems), 11 (21.56%), 17 (33.33%), 4 (7.84%), 1 (1.96%), and 18 (35.31%) systems were in Asia, Europe, Africa, the continent of Australia, and related to America, respectively, as seen in Table 3 and Figure 2.

Asia

In the Asia continent, Afghanistan has a facility-based maternal and perinatal health care monitoring system (BABIES) in 2002, as a popular hospital-based system. The creation of the system aimed to enhance the quality of healthcare services and reduce mortality [21]. In China, most of the surveyed popular and

Table 2: Data elements definitions in neonatal prematurity registries and databases.

Date elements	Description
Important registry information	Continent, region, Registry or database name, Acronym, Year of establishment, Resource maintain.
Scope	Nation-wide, Government-wide
Type of Registry	Population or Hospital-based
Important variables	Maternal characteristics: demographic (age, parity, weight, gestational age, ethnicity), society, and economic elements.
	Pregnancy data and information
	Neonate information
	Clinical information
	Administrative information
	Death information

Table 3: Main Evidence.

Ref. No	Continent	Registry, database name, or abbreviation	Year of establishment	Scope	Registry type	Resource maintains
[21]	Asia / Afghani- stan	Facility-based maternal and perinatal health care surveillance system (BABIES)	2002	Popular wide	Hospital- based	Women's hospital quality assurance team
[22]	America / Ohio	Pediatric Health Information System. (PHIS)	2006	Popular wide	Population- based	Department of Health
[23]	America / United States	National Assisted Reproductive Technology Surveillance System. (NASS)	1995	Popular wide	Population- based	U.S. Department of Health and Human Services Centers for Disease Control and Prevention
[24]	America / Arkansas	Pediatric Health Information System (PHIS)	1999	Popular wide	Population- based	AHRQ (Agency for Healthcare Research and Qualities)
[25, 26]	America / Wash- ington	Washington State Immunization Information System. (WAIS)	1991	Govern- ment-wide	Hospital- based	Washington State Department of Health
[27]	America/ Texas	Pediatric Health Information System. (PHIS)	2001	Govern- ment-wide	Hospital- based	AHRQ
[28]	America / North Carolina	Case Management Information System. (CCNC's)	2011	Popular wide	Population- based	AHRQ
[29]	America / Monte- video / Uruguay	Perinatal Information System Database of the Latin American Centre for Perinatology and Women's Reproductive Health. (CLAP/MR)	1970	Popular wide	Population- based	Pan American Health Organization (PAHO)
[30]	Africa / Ethiopia	Dabat Health and Demographic Surveillance System. (HDSS)	1996	Popular wide	Population- based	Ethiopian Public Health Association.
[31, 32]	Europe / Italy/ Umbria	regional Standard Certificate of Live Births in Umbria (SCLB)	1990	Govern- ment-wide	Population- based	Italian Ministry of Health
[33]	Asia / Bangla- desh Chakaria	Chakaria Health and Demographic Surveillance System. (CHDSS)	1994	Popular wide	Population- based	International Centre for Diarrheal Disease Research, Bangladesh (ICDDR)
[4]	Asia / China Beijing	Chinese Maternal and Newborn's Health Monitoring System. (MNHMS)	1988	Govern- ment-wide	Population- based	National Health and Family planning Commission (NHFP) & Alliance for Health Policy and Systems Research (AHPSR)

Ref. No	Continent	Registry, database name, or ab-breviation	Year of establishment	Scope	Registry type	Resource maintains
[34]	Asia / China Beijing	China's Information System of Prevention of Mother-to-Child Transmission of Syphilis management. (PMTCT)	1980	Popular wide	Population-based	National Center for Women and Children's Health, China (CDC)
[35]	Asia / China/ Wuhan	The Electronic Perinatal Health Care Information System. (EPHCIS)	1994	Popular wide	Population-based	Wuhan Medical and Health Center for Women and Children (WMHCWC)
[36]	Asia / China / Guangzhou	Guangzhou Perinatal Health Care and Delivery Surveillance System (GPHCDSS)	2000	Govern-ment-wide	Population-based	Guangzhou Women and Children's Health Information Center
[37]	Europe / Sweden	Swedish Medical Birth Register (SMBR)	1973	Popular wide	Population-based	Swedish National Council-based Epidemiology Center for Health and Welfare Population
[37]	Europe / Sweden	Prescribed Drug Register (PDR)	2005	Popular wide	Population-based	Center for Health and Welfare Population
[37]	Europe / Sweden	Cause of Death Register (CDR)	1997	Popular wide	Population-based	WHO
[37]	Europe / Sweden	National Patient Register	1987	Popular wide	Population-based	Center for Health and Welfare Population
[38-40]	Europe / France	Programmed de medicalization des systems information (PMSI)	1997	Popular wide	Hospital-based	Ministry of Health
[41]	America / Canada	Canadian Preterm Birth Network (CPTBN)	2017	Popular wide	Population-based	CIHI (Canadian Institute for Health Information)
[41]	America / Canada	discharge abstract database (DAD)	1963	Popular wide	Hospital-based	CIHI
[42]	Canada / Nova Scotia	Nova Scotia Atlee Perinatal Data-base (NSAPD)	1986	Govern-ment-wide	Hospital-based	Fertility Care Program
[14]	Asia / Pakistan	Pakistan Demographic Survey (PDS)	1997	Popular wide	Population-based	Federal Bureau of Statistics (FBS)
[43]	America / Peru	Perinatal Information System [16]	2000	Popular wide	Hospital-based	University of Pennsylvania and the Universidad Peruana Cayetano Heredia

Ref. No	Continent	Registry, database name, or ab-breviation	Year of establishment	Scope	Registry type	Resource maintains
[44]	Europe / Spain	European Information System (EuroNeoStat)	2002	Popular wide	Population-based	Health and Consumer Protection Directorate General (DG SANCO)
[45]	Europe / Spain	del sistema de vigilancia de las sepsis nosocomiales en (RNMBP (NeokisSES))	2005	Popular wide	Population-based	Spanish Society for Neonatology
[46]	Europe / Spain	Spanish National Health Service (Sistema Nacional de Salud) (SNS)	1986	Popular wide	Population-based	Ministry of Health and Social Policy
[47]	Europe / Scotland	discharge summaries (SMR2)	1975	Popular wide	Hospital-based	Scottish Health Service Common Services Agency.
[48]	Europe / Scotland	Scottish Birth Record (SBR)	2003	Popular wide	Population-based	NHS Net (National Health Service)
[49]	Europe / Scotland	Universal Newborn Hearing (UNHS)	2005	Popular wide	Population-based	NHS Net
[50]	America / Brazil / São Paulo	Live Births Information System (Sistema de Informações de Nascidos Vivos (SIMASC))	1990	Popular wide	Population-based	Federal Bureau of Statistics (FBS)
[51]	America / Brazil / Rio de Janeiro	Live Births Information System (Sistema de Informações de Nascidos Vivos (SIMASC))	1990	Popular wide	Population-based	Federal Bureau of Statistics (FBS)
[52]	America / Brazil / Rio de Janeiro	Unified Health System	1990	Popular wide	Population-based	The Ministry of Health (MH)
[53]	America / Brazil / Porto Alegre	Information System on Live Births of the Municipal Health Department (ISLBMHD)	1990	Popular wide	Hospital-based	Municipal Health Department
[54]	Africa / Uganda	Demographic and Health Surveys (DHS)	1990	Popular wide	Hospital-based	government health facilities and maternal health services
[55, 56]	Europe / Slovenia	National Perinatal Information System of Slovenia (NPIS)	1968	Popular wide	Hospital-based	National Institute of Public Health (Slovenia)
[57]	America / Pennsylvania	Certificate of Live Births (CLBs)	1963	Popular wide	Population-based	Department of Health
[58]	Europe / Italy / Lombardy	Hospital Discharge database (SDO)	1991	Popular wide	Population-based	Regional Health System

Ref. No	Continent	Registry, database name, or ab-breviation	Year of es-tablish-ment	Scope	Registry type	Resource maintains
[59]	America / Brazil/ Para-ná	Mortality and Live Birth Information System (SLBIM)	1990	Popular wide	Population-based	Federal Bureau of Statistics (FBS)
[60]	Africa / Kenya / Nairobi	Nairobi Urban Health and Demographic Surveillance system (NUHDSS)	2002	Popular wide	Population-based	African Population and Health Research Center (APHRC)
[61]	Asia / India/ Kar-nataka	maternal and newborn health registry (MNHR)	1992	Popular wide	Population-based	Ministry of Health
[62]	Europe / Norway	Medical Birth Registry of Norway. (MBRN)	1967	Popular wide	Hospital-based	Norwegian Institute of Public Health
[63]	Asia / Sri Lanka	Yellow form	2009	Popular wide	Hospital-based	WHO Collaborating Centre
[63, 64]	Asia / Taiwan	Taiwan National Medical Birth Register database (TNMBRD)	1995	Popular wide	Population-based	Maternal and child health research in Taiwan.
[65]	Europe // Island	Rhode Islands's integrated child health information system (KID-SNET)	2005	Popular wide	Population-based	Department of Health
[66, 67]	Europe / Finland/ Helsinki	Medical Birth Register (MBR)	1983	Popular wide	Population-based	National Institute for Health and Welfare (THL)
[68]	America / Florida	Pediatric Clinical Data Warehouse (PCDW)	2009	Popular wide	Population-based	Baylor Research Institute
[69]	Africa / Ghana	Dodowa Health and Demographic Surveillance System (DHDS)	1990	Popular wide	Population-based	Government of Ghana and the British Overseas Development Agency (ODANow DFID)
[70]	Asia / Japan	Japan Society of Obstetrics and Gynecology Perinatal Database. (JSOG)	1979	Popular wide	Population-based	Ministry of Health, Labour and Welfare
[71]	Australia / New Zealand	Australian and New Zealand Neo-natal Network. (ANZNN)	1994	Popular wide	Population-based	National Health and Research Council's (NHMRC)

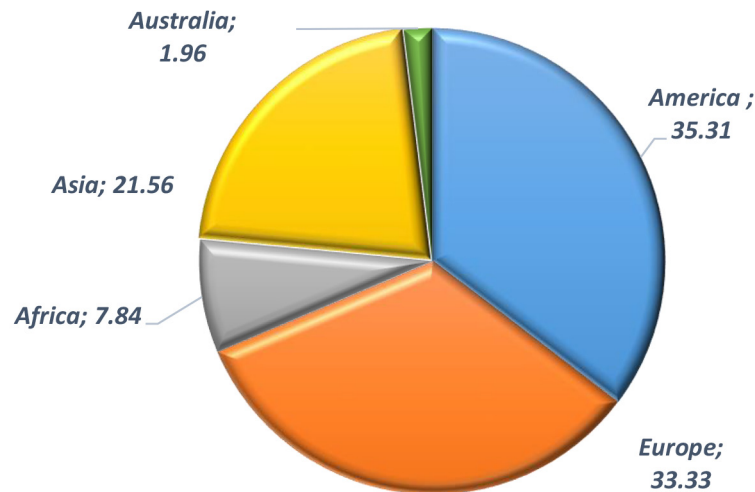


Figure 2: Division of existing registration systems based on 5 continents

population-based systems were used in different provinces. Among these, the MNHMS system was under use on a population-based basis since 1988 in six provinces of China. This system was created in Beijing, China, to monitor pregnancy care and review results. China's information system was also established nationally in Beijing in 1980 to prevent mother-to-child transmission of syphilis. It was then used as a national system to prevent the transmission of syphilis to infants [4, 34, 36].

America

In continental America, numerous national and state systems were established to record and maintain data on outpatients and inpatients, including the following. The first system was the PHIS information system, containing management and pharmaceutical data from 43 pediatric hospitals that are members of the Children's Hospital Association with approximately 85% of all independent children's hospitals in the United States [50, 51, 59]. The PHIS system was used as a national, population-based system in Ohio (since 2006) and Arkansas (since 1999) [22, 24]. According to the present study, the purpose of creating this system was child care management and

epidemiological studies.

Europe

The oldest system in continental Europe was created in 1967 in Norway and then in 1968 in Slovenia. Most of these systems were created to study the health factors and diseases of children as well as infants and contained both maternal and neonatal [55, 56, 62].

Africa

In Africa, Ethiopia has been using a national and population-based system since 1996, Uganda since (national and population-based) 1990, Kenya since 2002 (popular and hospital-based), and Ghana since 1990 (national and population-based). Different studies were also conducted on each of the systems, and the results were published [30, 54, 60, 69].

Australia

In Australia, the ANZNN system was established in New Zealand in 1994 as a national, population-based system to maintain and promote neonatal health [71].

Base on this research's finding the oldest systems were implemented in 1963 in Norway and Pennsylvania, while the newest system, the Canadian Preterm Birth Network, was

established in 2017. Regarding the scope of registry systems, 44 (86.27%) out of the 51 systems were popular-wide, and the rest were provincial-wide. Based on the results, of the 51 systems, the largest number of systems was population-based (n=39, 76.47%), and the systems were hospital-based. Most systems (68%) contained only clinical data, 23% management data, and 12% financial data.

In this study, the Minimum Data Set (MDS) was classified into two main categories, including maternal data category and newborn data category (Figure 3) respectively in four and eight main classes and several subclasses (Figures 4 and 5).

In the maternal part of the data, subclasses were categorized into demographic, prenatal, pregnancy, delivery, and childbirth as seen in Figure 4.

Further, in the newborn part of the data, subclasses were categorized to eight classes as seen in Figure 5.

Discussion

A patient registry is an organized system that uses observational study methods to collect

uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, serving a predetermined scientific, clinical, or policy purpose [72]. Registries are more comprehensive than similar hospital minimum data sets, such as those of New Zealand, England and France have more data elements, especially in the legal, incident, and geographic data classes [40, 73, 74]. Well-defined data collection was used for patient registration, medical center identification, insurance and reimbursement, medical research, outcome evaluation, and administrative reports [75].

All systems studied introduced some kinds of minimal data elements. In some systems, only the clinical aspects required for specific or cohort studies were addressed. However, some other systems investigated other aspects of information, such as management, financial, and health information. In this study, the Minimum Data Set (MDS) was classified into two main categories, including maternal data category and newborn data category, respectively in four and eight main classes and several subclasses in Figures 4 and 5 at the top. The MDS was categorized into 12 different data classes based on studied registries, expert focus panels, and patient hospitals. The proposed minimum data set for the prematurity information management system contains clinical data in addition to administrative plus financial data of patients.

In the maternal part of the data, subclasses were categorized into demographic, prenatal, pregnancy, delivery, and childbirth as seen in Figure 4. Further, in the newborn part of the data, subclasses were categorized to eight classes, including 1) demographic data (record no, national code, name, sure name, father name, newborn gender, mother nationality, father nationality, and birth place), 2) admission data (hospital name, refer from, refer to, admit status, and doctor name), 3) birth data (GA, BW, BH, HC, VS, apgarmin1, apgarmin5, newborn count, delivery method, and

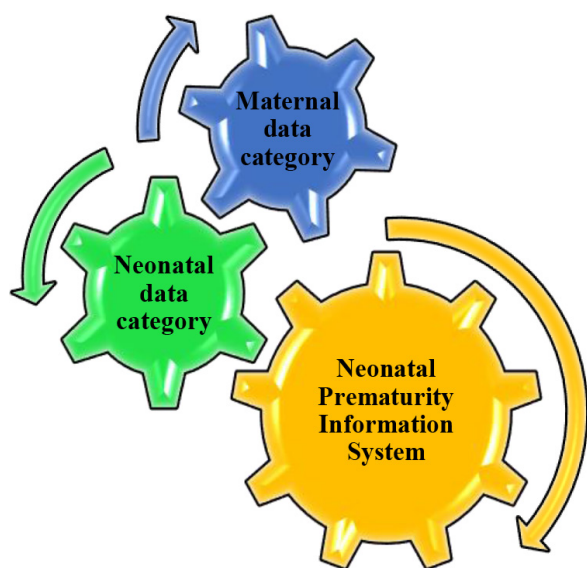


Figure 3: Main Framework of Neonatal Prematurity Information System

Premature Infants Information System Framework

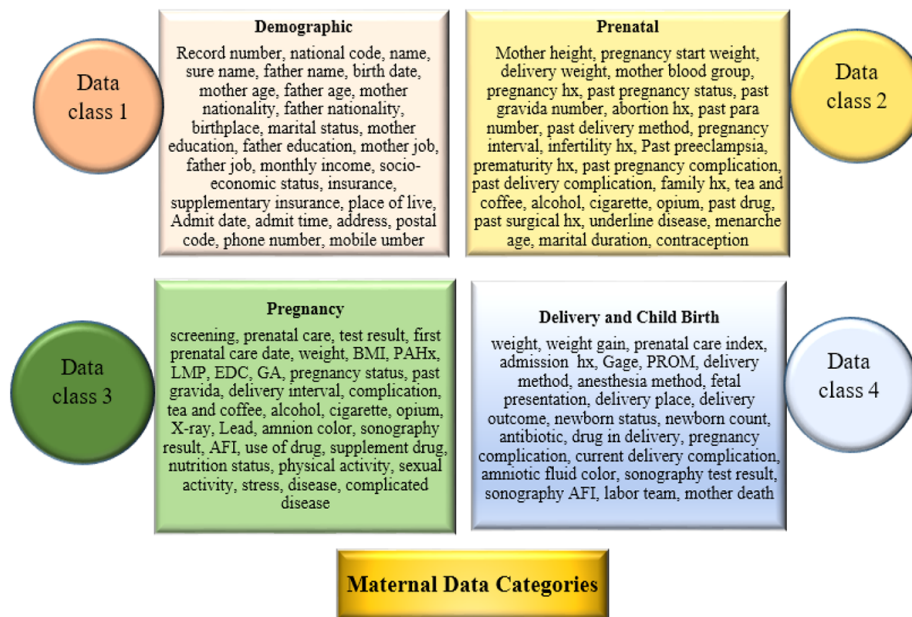


Figure 4: Maternal Data Element framework for Iranian Neonatal Prematurity Registry

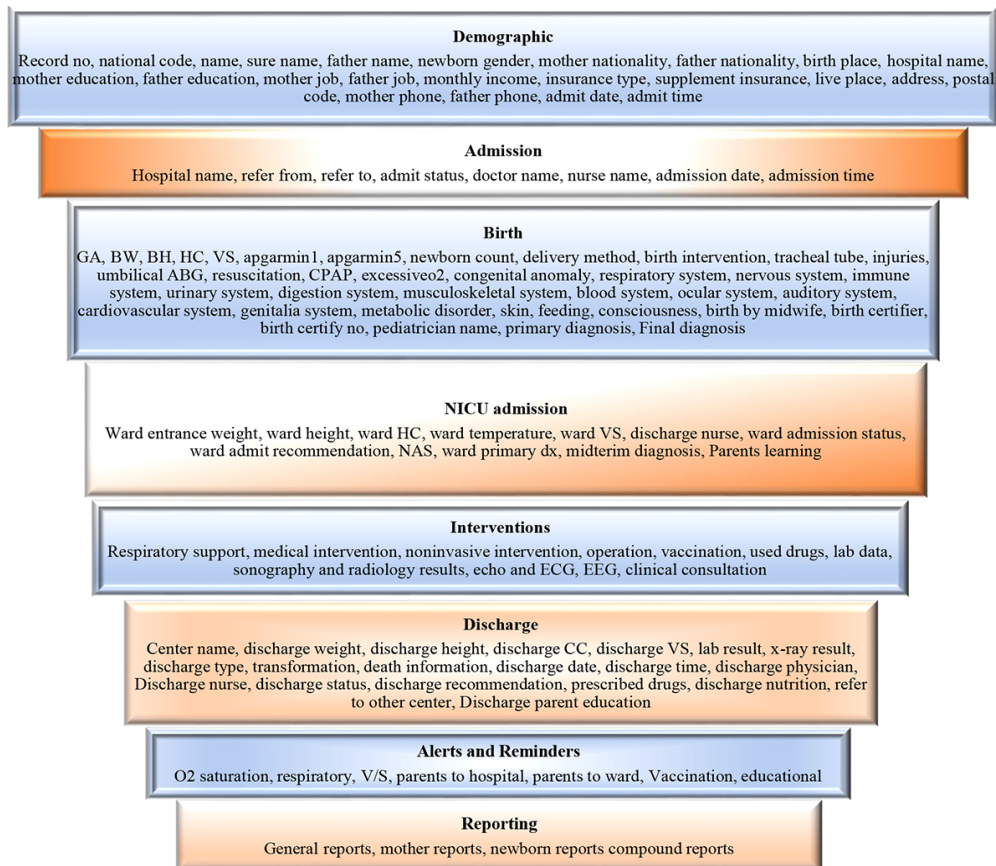


Figure 5: Neonatal Data Element framework for Iranian Neonatal Prematurity Registry

birth intervention, 4) the NICU admission data (ward entrance weight, ward height, ward HC, ward temperature, ward VS, discharge nurse, and ward admission status), 5) interventions data (respiratory support, medical intervention, noninvasive intervention, operation, and vaccination), 6) discharge data (center name, discharge weight, discharge height, discharge CC, discharge VS, lab result, X-ray result), 7) alerts and reminders data (O₂ saturation, respiratory, V/S, parents to hospital, parents to ward, and vaccination), and 8) reporting data (general reports, mother reports, newborn reports, and compound reports) as seen in Figure 5.

All types of identity and demographic, socioeconomic, financial, and administrative data along with clinical data are investigated in designing the minimum data set of this system. While in many previous systems, they did not receive much attention and were more supported clinically [40, 73, 74]. However, current systems can fulfill the needs of owners and investors in conducting clinical trials, these systems cannot directly assist physicians and healthcare teams in deciding and educating parents of infants. Thus, researchers recommend adding a module to the available systems to perform this.

This research contains some limitations as follows: 1) the identification and comparison of data for researchers were hard to work since the sparse dispersion of papers related to the MDS of premature infant's registry and systems of surveillance, 2) the lack of access to databases in the current context of sanctions, the lack of the authors' cooperation to grant access to some systems and related sites, and the difficulty of persuading authors to authorize access to the systems.

Conclusion

Registry systems are important to many users, including policymakers, executives, planners, health care providers, and patients. These systems contain valuable information

and knowledge that especially help health policymakers in the design and development of future health care information systems for disease management. Also, registration is mentioned as an essential key to improving digital health systems, and communication between doctors, patients or parents. To the best of our knowledge, the present study is a comprehensive study that has systematically examined prematurity-based registrations. With this research, we found that in regard to the preparation of output reports for doctors and care providers, registries play an important role in documenting the data and information of infants to improve their health status during the care period. Investing in the design and development phase of creating data systems can improve the performance of care standards and thus reduce mortality and the cost of premature babies. In particular, the production of information systems in low- and middle-income countries, which are likely to experience a growing trend in the field of neonatal morbidity and mortality and its complications, is of great importance.

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Authors' Contribution

Sh. Pahlevanynejad, R. Safdari and N. Danaee contributed to the conceptualization and study design, data collection and interpretation, drafting of the paper, and critically revising several drafts of the paper for improvement of its intellectual content. All authors have read and approved the submitted and revised final version of the manuscript.

Ethical Approval

The current study was the result of the first phase of the author's Ph.D. dissertation, which is done in the cooperation of TUMS with Semnan University

of medical sciences with research ethics certificate ID: IR.TUMS.SPH.REC.1399.126.

Conflict of Interest

None

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