

# Designing a Software for Registry of Pregnant Women with Heart Disease in Iran and Preliminary Results

## Abstract

Heart disease in pregnancy is an important health issue worldwide which needs precise care to improve pregnant women health care and reduce maternal mortality rate (MMR). As we know registries play an important role in improvement of health care, so we decided to design a software to take the first step for having a national registry for pregnant women with heart disease in Iran and classify them in a more effective way to reduce mismanagements. A windows-based software with C# language programming was designed and implemented by a group of specialists included two experienced cardiologists, a skilled gynecologist, and a proficient medical doctor programmer. Since the launch of the software, information for 500 pregnant women with heart disease has been entered. The most common types of heart disease in order were congenital heart disease, prosthetic heart valves, valvular disease, and cardiomyopathies. The software developed by our team provides a comprehensive and efficient tool for managing patients with heart disease in pregnancy. The use of this software can help identify high-risk patients early on, leading to better patient outcomes and ultimately contributing to the global goal of reducing MMR. In the field of pregnant women with heart disease, gathering large and accurate data over time can be utilized in artificial intelligence for analysis.

**Keywords:** Artificial intelligence, heart disease, maternal mortality rate, pregnancy, pregnancy registry, software

Submitted: 23-Jun-2024

Revised: 28-Nov-2024

Accepted: 18-Dec-2024

Published: 10-Jul-2025

## Introduction

Maternal health and the reduction of maternal mortality rate (MMR) are a crucial global health issue.<sup>[1]</sup> According to recent studies, heart disease is becoming the leading cause of maternal death worldwide, especially in developed countries.<sup>[2-9]</sup> Hemodynamic changes during pregnancy can negatively impact the normal function of the heart, particularly in women with preexisting heart disease, exacerbating the condition.<sup>[10-15]</sup> According to the latest studies, 1%–4% of pregnancies are affected by cardiovascular disease.<sup>[2,16-18]</sup> In developing countries, rheumatic heart disease (RHD), hypertensive heart disease (HHD), and congenital heart disease (CHD) are common causes.<sup>[12,17,19-21]</sup>

Insufficient and substandard healthcare is a major factor contributing to 50% of maternal mortalities, which are preventable, according to the UK study. Lack of access to a standard

healthcare center, overlapping of heart disease symptoms with normal pregnancy symptoms, and difficulty in diagnosing heart disease for the first time in pregnant women are other effective factors.<sup>[16,22-25]</sup>

The World Health Organization (WHO) has set a global health goal to reduce the MMR to 70 deaths per 100,000 live births by 2030 (WHO, 2015). To achieve this goal, each country needs to develop a plan based on its socioeconomic status, cultural environment, and healthcare resources.<sup>[26-29]</sup>

One of the key challenges in addressing maternal mortality related to heart disease is the lack of adequate data and information about these cases. To address this challenge, many countries have implemented registries to collect data on pregnancies in women with heart disease. These registries have proven to be valuable tools for improving the quality of care and reducing MMRs.<sup>[30-36]</sup>

The largest registry in cardiac disease in pregnancy is registry of pregnancy

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## Access this article online

**Website:** www.jmssjournal.net

**DOI:** 10.4103/jmss.jmss\_43\_24

## Quick Response Code:



**How to cite this article:** Kalani M, Mahdikhoshouei F, Bahrami P, Khajouei AS, Movahedi M, Mehdipour S, et al. Designing a software for registry of pregnant women with heart disease in Iran and preliminary results. J Med Signals Sens 2025;15:21.

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and cardiac disease (ROPAC) registry, which includes information on pregnant women with heart disease (PWWHD) from 28 countries, mostly developed countries. Since the implementation of ROPAC, many research studies based on its database have been conducted, leading to better healthcare.<sup>[10]</sup>

The success of these registries is based on the availability of accurate and comprehensive data. However, the lack of standardized data collection methods and tools can limit the usefulness of these registries. In addition, the lack of interoperability between different registries can make it difficult to share and compare data between countries.<sup>[30]</sup>

To address these challenges, the development of a national registry for pregnancies in women with heart disease (PWWHD) is crucial. A national registry would provide a standardized approach to data collection, allowing for better comparisons and analysis of data.<sup>[30,37-39]</sup> It would also facilitate the sharing of data between different healthcare providers and institutions, improving the quality of care and reducing MMRs.<sup>[30]</sup>

Our software is designed to collect and manage data on pregnancies in women with heart disease in Iran, providing a platform for the development of a national registry. By collecting comprehensive data on these cases, we aim to identify high-risk patients early on and provide timely and effective interventions to reduce maternal mortality and complication rate of mother and fetus.

## Methods

### Implementation

Our software has been developed on the .NET Windows platform, which offers a wide range of features and benefits for users. The Windows interface provides a more immersive user experience with a rich graphical interface, intuitive menus, shortcut keys, and other controls that allow for faster navigation and response times compared to web-based software. The software has been coded using the Visual C#.NET programming language, which is an object-oriented, type-safe programming language that offers a modern and flexible approach to software development.

To ensure a streamlined and efficient development process, we have utilized the WPF DevExpress toolkit for the user interface. This toolkit offers a fast and structured approach to software development, allowing us to quickly implement and test new features and functionality. The result is a user-friendly interface that is both visually appealing and highly functional.

In addition, we have used a SQL-based relational database management system as the database for our software. This allows for efficient data storage and retrieval, ensuring that the software can handle large volumes of data while maintaining optimal performance. Overall, our implementation approach has been designed to deliver a

high-quality software solution that meets the needs of our users.

### Design

To design and implement the software, a multidisciplinary team consisting of two experienced cardiologists, a skilled gynecologist, a proficient medical doctor programmer and a team of researchers collaborated in a comprehensive effort. The team first carefully analyzed the patients' medical records and conducted multiple meetings, discussing crucial information relevant to the diagnosis, treatment, and follow-up of the patients. Subsequently, based on the literature review of heart diseases in pregnancy, the team developed a comprehensive unit form for recording and storing the patients' data in the software. The form includes various important aspects such as patient medical history, family history, obstetric history, physical examination, laboratory test results, sonography data, and other relevant clinical information, which are securely stored as an electronic health record in the database.

To ensure the completeness and accuracy of the data, the team meticulously reviewed the medical records of patients who had previously visited the Alzahra hospital cardiac center, and extracted over 500 patients' data, who met the inclusion criteria and entered into the software. The inclusion criteria were defined based on previously published guidelines and expert opinions. All pregnant women with CHD, Valvular heart disease (including rheumatic or prosthetic valve), Cardiomyopathies such as dilated, hypertrophic and peripartum, coronary artery disease, arrhythmia (brady or tachy arrhythmia), pulmonary hypertension, aortic disease, and HHD were included in the study. On the other hand, the exclusion criteria were patient dissatisfaction and incomplete medical records.

### Function

Our software serves as a pilot for a national registry, and we have already started collecting data using it. The software requires several inputs, including patient demographics such as age, gender, race/ethnicity, and socioeconomic status. These factors can impact a patient's health outcomes and may help identify disparities in care. We also collect medical history and comorbidities, such as past medical conditions, pregnancy history, vaccination and drug history, and any other health conditions that may impact treatment and outcomes [Figure 1]. Cardiac disease status is also recorded, including information on cardiac disease diagnosis, cardiac surgery, and patient classification based on New York Heart Association and WHO class. In addition, laboratory and diagnostic test results are recorded, such as echocardiography, exercise tests, cardiac magnetic resonance image, angiography and cardiac catheterization data, which can provide important information for diagnosis and treatment planning.

Treatment information, including evaluation and physical examinations, treatments prescribed or administered to

the patient at each visit during pregnancy, advice and recommendations on diet, next appointments, red flags, and more, is also recorded. Medications prescribed and administered are also tracked. We record any adverse events or complications that occur during the patient's treatment, which can help identify areas for improvement in care. Finally, follow-up and outcomes data are recorded, such as readmissions, mortality rates, and other health outcomes, as well as delivery and child information, including the date of delivery, gestational age, section or natural vaginal delivery, and child data such as weight and neonatal intensive care unit admission.

Our software is designed to provide a comprehensive and detailed database of patient information related to maternal health and heart disease during pregnancy. The software generates several outputs that can be used to identify areas for improvement in patient care, develop targeted interventions for high-risk patients, and provide valuable data for clinical trials and research studies, as well as artificial intelligence (AI) technology.

The software provides summary statistics of patient characteristics, including demographic information and other relevant factors, and incidence and prevalence rates of specific diseases or conditions within the patient population being treated. We also track treatment patterns and effectiveness, including information on specific treatments prescribed or administered to patients and their effectiveness in achieving desired outcomes. Long-term outcomes data are also tracked, including patient survival rates, recurrence rates, and other long-term outcomes. We identify high-risk patient groups and any variation in the treatments prescribed or administered to patients, which can help identify areas for improvement in care. Finally, we provide research data that can be used in clinical trials or other research studies to improve our understanding of specific diseases or conditions and how they are best treated.

By entering a large amount of data into the software, in future, we can also use AI technology to generate additional

outputs, such as identifying areas for improvement in patient care and outcomes, treatment recommendations based on patient characteristics and outcomes data, and clinical decision support tools that can aid in diagnosis and treatment planning, providing clinicians with relevant information to inform their decisions.

## Results

Since the launch of the software, information for 500 pregnant women with heart disease has been entered. The prevalence of heart disease in pregnant women are reported in Table 1 and Figure 2 based on the data collected from this software.

## Discussion

MMR is an important criterion for evaluating a country's health system quality, and fortunately, Iran was one of the most successful countries in reducing MMR from 123 in 1990 to 17 in 2015.<sup>[40-42]</sup>

According to studies conducted in Iran and worldwide, most causes of MMR are preventable, so it is still worthwhile to work on this issue and reduce these factors.<sup>[40,43-45]</sup> To achieve this goal and plan efficient policies, it is essential to have enough and valid information. The UK study in 2019 found that 23% of MMR were due to heart disease.<sup>[45]</sup> In a systematic review study in Iran, heart disease was identified as a second factor of indirect cause of MMR and was responsible for 8% of deaths.<sup>[42]</sup> In recent years, due to an increase in pregnancy age, better care of patients with CHD and unhealthy lifestyles such as obesity, cardiovascular disease has increased.<sup>[26,46]</sup> Fortunately, heart diseases are preventable causes of MMR.<sup>[45]</sup>

Registries provide an opportunity to carefully evaluate the care and treatment provided to pregnant mothers, making them a key factor in improving the healthcare process. The data obtained from these registries show the problems of each system so that health policymakers can act in the right direction. Comprehensive data related to pregnant

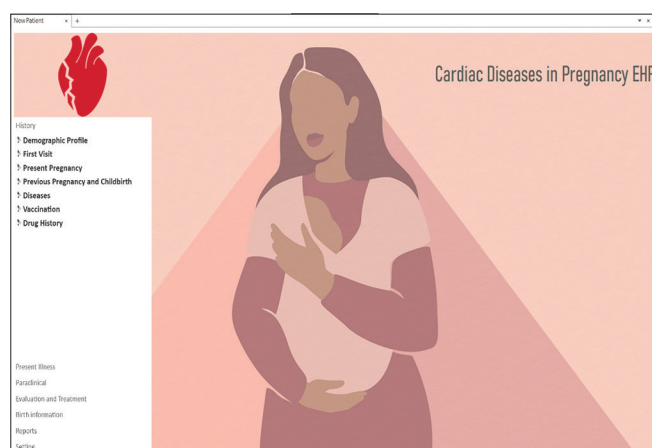


Figure 1: Home page of software. EHR: Electronic health record

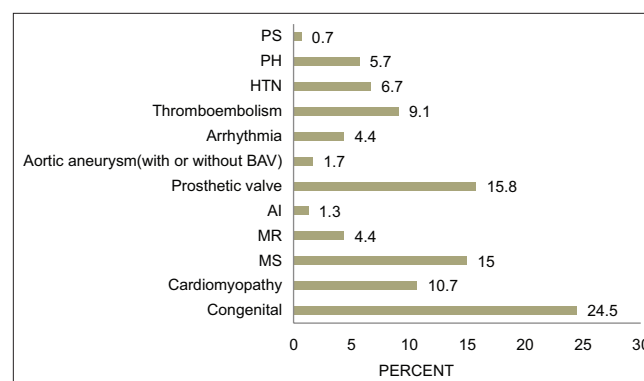


Figure 2: The prevalence of heart disease in pregnant women. HTN: Hypertension, AI: Artificial intelligence, MR: Mitral regurgitation, MS: Mitral stenosis, BAV: Bicuspid aortic valve, PH: Pulmonary hypertension, PS: Pulmonary stenosis

**Table 1: Frequency of heart diseases in pregnancy (software extracted data)**

Frequencies of heart disease	
Disease	Frequency (%)
Congenital	
Left to right shunt	
ASD	
Repaired	3.4
Nonrepaired	6.7
VSD	
Repaired	1.7
Nonrepaired	1.7
PDA	0.3
Left ventricular outflow tract lesions	
Valvular AS	1.7
Subvalve AS	0.7
Cyanotic	
TOF	3
FONTAN	0.3
TGA	1.7
Ebstein	2
TA	0.3
Double outlet RV	0
Coarctation of aorta	
Repaired	0.7
Nonrepaired	0.3
Cardiomyopathy	
DCM	6
PCM	3.7
Hypertrophic	1
Prosthetic valve	
Mechanical valve	13.1
Biological valve	2.7
Arrhythmia	
Brady arrhythmia	1
Tachy arrhythmia	3.4
HTN	
Chronic	2
Gestational	4.7
MS	15
MR	4.4
AI	1.3
Aortic aneurysm (with or without BAV)	1.7
PH	5.7
PS	0.7
Thromboembolism	9.1

ASD – Atrial septal defect; VSD – Ventricular septal defect; PDA – Patent ductus arteriosus; AS – Aortic stenosis; PCM – Prepartum cardiomyopathy; DCM – Dilated cardiomyopathy; RV – Right ventricle; TA – Tricuspid atresia; TGA – Transposition of great arteries; TOF – Tetralogy of fallot; HTN – Hypertension; MS – Mitral stenosis; MR – Mitral regurgitation; AI – Aortic insufficiency; PH – Pulmonary hypertension; PS – Pulmonary stenosis; BAV – Bicuspid aortic valve

women with heart disease (PWWHD) are available in developed countries through registries, while in developing countries such as Iran, this information is not effectively

available.<sup>[10,26,32,46-48]</sup> According to studies, common heart disease is different in each country. RHD is more common in developing countries, and CHD is more common in developed countries.<sup>[46]</sup> Due to the differences in the cultural and economic structure of each country and the different prevalence of heart disease, each region needs to set up a comprehensive data collection system specific to it so that it can respond to the needs of its health system.<sup>[26]</sup>

During the review of studies, it was found that there was no registry in Iran to collect information on pregnant women with heart disease. As a result, a software system was launched in 2020. The software system is similar to its international counterparts and covers the treatment process of pregnant mothers up to 40 days after delivery.<sup>[10,26,46]</sup> Comprehensive information on the health of pregnant mothers includes the history of the disease and associated diseases, surgical and drug records, previous pregnancies, and clinical and paraclinical examinations. According to the information obtained from this software, 500 patients were examined, and based on software result, the prevalence of heart disease in pregnant mothers is as follows which shows that the most common heart disease in pregnancy in Iran is similar to developed countries.<sup>[46]</sup>

Another key point is that the causes and influencing factors leading to a disease in each patient with the same diagnosis may vary. Furthermore, considering that diagnosis alone is not sufficient for treatment, and the causes leading to this diagnosis will also have an impact on treatment, and as a result, the treatment of one patient with another patient despite having the same diagnosis may differ. When we can identify these paths and the causal relationship of each diagnosis with the underlying causes in each patient, we can understand which treatment is more suitable for which patient. To perform this process and find these paths and the relationship between the causes of the disease, several specialists in this field examine the causes of the disease in each patient and suggest a path for each diagnosis, which with the treatments performed, the patient's prognosis and other information recorded in the system, we will have access to a large dataset. By using AI technology, these data can be used to introduce a comprehensive classification of cardiac diseases with appropriate treatment for each branch and improve the care and treatment of patients.

AI has rapidly advanced in the field of medicine over the past 20 years, with various applications being developed. AI is a broad term that encompasses subgroups such as machine learning and deep learning. By using large data sets, machine learning can identify patterns and relationships between data, and after training, it can analyze new data in fields such as disease diagnosis and classification, as well as recommending treatment plans.<sup>[49-52]</sup>

In the field of pregnant women with heart disease (PWWHD), gathering large and accurate data over time can be utilized in AI for analysis. One of our goals in designing



this software is to have an information base for AI training, in addition to the aforementioned objectives.

## Conclusion

MMR is a significant indicator of the quality of a country's healthcare system. Iran has made commendable progress in reducing MMR, but there is still place for improvement. Preventable causes of MMR, such as heart disease, need to be addressed through efficient policies and adequate data collection. Registries provide a valuable source of information that can help policymakers make informed decisions and improve the healthcare process. However, the lack of comprehensive data related to pregnant women with heart disease (PWWHD) in developing countries such as Iran is a major challenge that needs to be addressed. The recently launched software system for collecting information on pregnant women with heart disease in Iran is a step in the right direction. It provides a comprehensive record of patients' health and classifies patients based on themselves, in an individualized path, which can lead to more effective and personalized treatments. By addressing these issues and working toward more effective healthcare policies, Iran and other developing countries can continue to make progress in reducing MMRs.

## Acknowledgments

The authors would like to thank the experts who participated in the study. We would also like to extend our appreciation to the patients whose data were used in the study.

## Financial support and sponsorship

Nil.

## Conflicts of interest

There are no conflicts of interest.

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