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COVID-19 Electronic Registry Systems in Iran: A Review

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Abstract

Introduction: Since the beginning of the COVID-19 epidemic in Iran, several electronic registration systems have been created to record the data of infected patients. This narrative review aimed to investigate the articles that described the COVID-19 electronic registry systems designed and implemented in Iran.

Methods: In this review, four electronic databases [Medline (accessed from PubMed), Scopus, Science Direct, and Web of Science] were searched till June 22, 2020, using specific MeSH terms and related keywords in English language. Considering the titles and abstracts, unrelated studies were excluded. The full texts of the remained studies were evaluated by authors, independently. Then, their findings were assessed and reported.

Results: Finally, four articles were enrolled, introducing four COVID-19 registries. These registries were designed and launched by Isfahan, Shiraz, Tehran, and Ilam Universities of Medical Sciences. They were different in design, the used algorithms for patients' management, recorded data, and methods of quality assurance.

Conclusion: Considering the differences between various registry systems designed for COVID-19 in Iran, it is recommended to develop a single web-based registry system by the Iran Ministry of Health and Medical Education to register and follow up the patients with COVID-19.

Keywords: Coronavirus, COVID-19, Registries, Iran

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Introduction

According to the definition provided by the World Health Organization (WHO), registry systems are a collection of documents containing similar information of unique individuals that are collected systematically and comprehensively to achieve predetermined and scientific, clinical, or political goals.[1] These structured systems were designed to collect data such as demographic characteristics, clinical history, and outcomes for a specific disease or condition or a particular exposure, which can be utilized to assess the identified events in the target population.[2-4] Furthermore, these systems can be used to evaluate the quality and cost-effectiveness of health services and formulate the necessary evidence for policy/decision-making purposes.[4,5]

Registry systems have been traditional pen-and-paper methods for field survey data collection over the past decade.[6] But, paper-based medical records might be incomplete, fragmented, difficult to find or read, and they need a lot of space for archives. Moreover, they cost a lot of money to record and data preservation. Since data management in this method is very inefficient, electronic registration systems have been introduced.[7-9]

Since 1950s, the number of disease registration systems has significantly increased, which can be attributed to the increasing attention to the effects of chronic diseases on populations' health. Today, healthcare systems use various computer software for managerial purposes as well as storing patients' information, which increases the access to data

and their analyses. The ultimate goal of these systems, often supported by the government and hospitals, is public health surveillance and research. Since 2014, the Ministry of Health and Medical Education (MoHME) of Iran has launched many registry systems for various diseases and health outcomes, which till now more than 50 systems have been confirmed and received financial support.[3] Meanwhile, for communicable diseases, several registries have been designed and launched in Iran.[10-12]

In December 2019, a novel type of coronavirus was emerged in Wuhan city, Hubei province (China). This pneumonic disease whose cause was unknown soon became a pandemic and was named COVID-19.[13-15] According to the WHO statistics, the virus has spread to at least 156 countries and it is introduced as a pandemic. On January 30, the WHO declared an international emergency for public health.[16] Despite all efforts, the disease spread to Iran.[17,18] Due to the ambiguities around the COVID-19 and contradictory recommendations,[19,20] there is a need to design and set up an electronic patient registration system. Since the beginning of this epidemic in Iran, several electronic registration systems have been generated to record the data of infected patients with COVID-19. This review aimed to investigate the articles that described the COVID-19 electronic registry systems designed and launched in Iran to get acquainted with the design aspects, the used algorithms for patients' management, recorded data, and methods of quality assurance.

Methods

In this review, electronic literature searches were conducted to identify all studies in the field of COVID-19 electronic registry systems in Iran. Hence, Medline (accessed from PubMed), Scopus, Science Direct, and Web of Science were four databases searched up till June 22, 2020, by three authors [RSM, HS, RSM]. MeSH Keywords used were ("COVID-19" OR "2019 novel coronavirus" OR "2019-nCoV" OR "severe acute respiratory syndrome coronavirus 2" OR "SARS-CoV-2" OR "2019nCoV" OR "Wuhan coronavirus") AND "registry*". Google search engine and "researchgate.net" were also reviewed manually to explore the grey literature [RSM, RS]. To ensure literature saturation, the reference lists of the included studies or relevant reviews identified through the search were scanned. No time restriction was considered for the searching, and all searches were performed in English. Studies, which were not relevant to the study's aim, written in a non-English language, or studies that considered other coronaviruses except COVID-19, as well as studies without available full-text were excluded, through reading the title and the abstract [RSM, MS, RSM]. The studies were selected independently and the results were discussed to make the final selection. After reading the full text of all potentially eligible articles, a final decision was made for each study. Also, the data extraction was performed by all authors. Any disagreement was discussed after the completion of the data collection process.

The following data were extracted from the included studies: study authors, name of a registry, source of registry, type, initiation date, patients, the algorithm of patient care, recorded data, follow-up duration, and quality assurance. A data extraction form was designed in a Microsoft Excel sheet 2013, by two authors [RSM, HS]. The disagreements were resolved, and then the obtained results were summarized [RSM].

Results

After careful screening, four articles were confirmed and enrolled in this review,[4,21-23] which are summarized in Table 1. These registries were designed and launched by Isfahan, Shiraz, Tehran, and Ilam Universities of Medical Sciences. They were different in design, the used algorithms for patients' management, recorded data, and methods of quality assurance. In the following, we will explain their various aspects.

Haghjooy Javanmard et al[4] designed and implemented a registry system called Isfahan COVID-19 Registry (I-CORE), which as noted by them, is the first comprehensive critical incident registry system for COVID-19 in Iran. This system collects data on patients with a definitive or suspected diagnosis of COVID-19 based on the temporary guidelines developed by WHO. All patients with a definitive diagnosis of COVID-19, regardless of clinical signs and symptoms, were defined as definitive patients. Patients without a definitive COVID-19 diagnosis were categorized as a suspected case if having one of the following conditions: (1) asymptomatic patients with acute respiratory illness and a history of travel during the past 14 days to areas that local spread of the COVID-19 is reported; (2) patients with presentations of acute respiratory illness who had contact with a definitive or suspected case of COVID-19 within 14 days before the onset of the symptoms; and (3) patients with acute respiratory infection who required hospitalization and had no other etiology to justify their clinical presentations. Data were collected using WHO questionnaires and protocols. The committee included the vice-chancellor of research, health, and treatment of Isfahan University of Medical Sciences, specialized physicians, nurses of hospital infection control, and health information technology staff control the quality assurance.

They reported that by March 11, 2020, data from 3,083 patients (56% male) with a definitive or suspected diagnosis of COVID-19 were recorded in the system. In total, 611 cases were definitive (61% male), with a mean ± standard deviation age of 58.44 (17.0) years (range; 14-99), of which about 5.6% of them died and 32.2% were discharged from the hospital. Not describing the details of the process of collecting data and not providing an algorithm for patient care are the disadvantages of this study. Also, the duration of patients' follow-up was not mentioned in the system.

Another electronic web-based registry system in Shiraz city (south of Iran) was designed by Akbari et al[21] to record data on suspected or confirmed COVID-19 patients. This system is approved by Shiraz University of Medical Sciences; it is designed based on a comprehensive form that was according to a checklist recommended by WHO. Inclusion criteria

Table 1. Summary of Studies Details

Author's Study (Year)	Name of the Registry	Source of the Registry	Type	Initiation Date	Patients	Algorithm of Patient Care	Recorded Data	Follow-up Duration	Quality Assurance
Haghjooy Javanmard et al (2020)[4]	Isfahan COVID-19 REgistry (I-CoRE)	Isfahan University of Medical Sciences	Not reported	February 2020	Patients with confirmed or probable COVID-19 from hospitals or syndromic surveillance system	NR	NR	NR	A committee included the vice-chancellor of research, health, and treatment of Isfahan University of Medical Sciences, specialized physicians, nurses of hospital infection control, staff of health information technology
Akbari et al (2020)[21]	COVID-19 Electronic Registry	Shiraz University of Medical Sciences	Electronic web-based	2020	Patients suspected or confirmed with COVID-19 referred to any healthcare center in Fars province, also included pregnant women and infants	Yes	Patients' demographic characteristics; chest CT scan findings; laboratory tests, complications during hospitalization, treatments, and ICU course Further investigations of patients with COVID-19: 1- All patients: Patients characteristics; Laboratory tests (complete blood count with differential, CRP, serum creatinine, liver function tests, ferritin, blood group, myoglobin, creatinine kinase, serum sodium, serum potassium, Mg, vitamin D); chest CT scan findings; complications; treatments 2- ICU admitted patients: Laboratory tests (PT, PTT, INR, D-dimer); ICU course sheet (APACHE score, SOFA score Types of oxygen therapy, Oxygen status, lung dynamics, advanced hemodynamic parameters with USCOM, Complication, and outcomes 3- Sepsis suspected: Laboratory tests (arterial blood gas, procalcitonin, blood culture)	During the hospitalization and one month after	A committee of specialists in all aspect control and monitor the data gathering process
Talebpour et al. (2020) [22]	Sina hospital COVID-19 Registry (SHCo-19R)	Tehran University of Medical Sciences (Sina hospital)	Hospital-based and electronic web-based	February 2020	Patients (>18 years) with suggestive symptoms of COVID-19 infection (fever, cough, dyspnea) with positive chest CT scan or positive PCR test	Yes	Patients characteristics, pre-hospital findings, chest CT scan findings, Laboratory tests, hospitalization and/or ICU courses, In-hospital outcomes, follow-up events, complications Further investigations of patients with COVID-19: 1- All patients: Laboratory tests (complete blood count with differential, CRP, serum creatinine, Na, K, Mg, vitamin D, liver function tests, troponin, ferritin, blood group); Electrocardiogram (ST-T change, arrhythmia); Chest CT scan findings 2- If myocarditis is suspected: Laboratory tests (LDH, CPK, Pro-BNP); Echocardiography (ventricular dysfunction, pericardial effusion) 3- In ICU admitted patients: Laboratory tests (PT, PTT, INR, D-dimer); ICU course sheet (APACHE score, SOFA score, types of oxygen therapy, oxygenation status, lung dynamics, advanced hemodynamic parameters with USCOM, complications, and outcomes 4- If sepsis is suspected: Laboratory tests (arterial blood gas, procalcitonin, blood culture x2)	One month after discharge	A committee of specialists check the national recommendations and monitor the data collection and the accuracy of data entry, permanently
Kazemi-Arpanahi (2020) [23]	COVID-19 registry	Ilam University of Medical Sciences	Electronic web-based	2020	NR	NR	1- Administrative data category (nonclinical): Sociodemographic (patient's name, father's name, age, sex, date of birth, place of birth, marital status, employment status, occupation, race/nationality, educational level, home address, postal/zip code, phone number); Identifier (national ID, visit number, social security number, physician ID); Patient disposition (admission date, reason for admission, type of admission, readmission, length of stay, discharge date, discharge status, underlying cause of death, date of death, discharge location, discharge prescribed drugs, date of follow-up) 2- Clinical data category: Diagnostic (disease history, comorbidity, disease status, disease severity status, case classification, sing and symptoms, days from exposure to symptom onset, time between diagnosis to treatment, date of diagnosis); exposure (exposed to high-risk agent, exposure history, date of exposure); physical examination (respiratory rate, temperature, blood pressure, heart rate, blood group, lung examination); medical/diagnostic procedures (oxygen support, Radiology, CT features, lung segment involvement, LAB test name, PCR result, test time)	NR	NR

Abbreviations: NR: not reported; PCR, polymerase chain reaction; CT, computed tomography; ICU, intensive care unit; PT, prothrombin time; INR, international normalized ratio; PTT, partial thromboplastin time; CRP, C-reactive protein; SOFA, Sequential Organ Failure Assessment; CPK, creatine phosphokinase; LDH, lactic dehydrogenase

consisted of fever, cough, and shortness of breath. COVID-19 infection should be confirmed through chest computed tomography (CT) scan and polymerase chain reaction (PCR) test. Recorded data include patients' demographic characteristics, results of the chest CT scan, laboratory tests, complications during hospitalization, treatment, and intensive care unit (ICU) courses. Data for the hospital stay and one-month follow-up were also recorded in the system. Moreover, in this system, the virtual status of the patients' family members was monitored through phone calls, to see whether they need screening and hospitalization or not. Data on pregnant women and neonates were recorded, as well. In addition to the patient care algorithm, the authors described the flowchart of risk assessment in pregnant women as well as infants of suspected or definitively diagnosed mothers, individually.

The authors reported that due to the unknown nature of the disease, treatment protocols and guidelines may change during the study implementation. For quality assurance, a team of specialists comprised of all related fields monitored the data collection process. One of the weaknesses was not providing statistical reports about the registered patients in the manuscript published by the authors so that it seems necessary to record, analyze and report the volume of the patients' data over a period of time to determine if the system is working properly or not. Also, one of the exclusion criteria is patients' dissatisfaction to record their data in the system, while recording data in the registry systems does not require obtaining the patients' consent and all data must be recorded, so that epidemiological analyses can be performed. Similar to the I-CORE system, it was not mentioned that who collected and entered the data.

Talebpour et al[22] developed a hospital-based system called Sina hospital COVID-19 Registry (SHCo-19) in Tehran, the capital of Iran. This system records data on clinical presentation, diagnostic measures, treatments, hospital courses, and the patients' follow-up who were referred to the emergency department of Sina hospital, affiliated with Tehran University of Medical Sciences, and one of the centers specially allocated to COVID-19 patients. The data were recorded retrospectively. The inclusion criteria included age ≥ 18 years with suggestive symptoms for COVID-19 (i.e. fever, cough, and dyspnea), chest CT scan indicating the infection, and a positive PCR test. For patients who are suspected of COVID-19, the chest CT scan, laboratory tests such as complete blood cells, C-reactive protein (CRP), serum creatinine and sodium and potassium, magnesium, vitamin D level, liver function tests, troponin, ferritin, and checking the blood group are performed. Other diagnostic modalities are used based on the predetermined protocols. During hospitalization, patients were monitored in terms of blood pressure, fever, respiratory symptoms, oxygenation, serum electrolytes, medications, and death. Meanwhile, complications that occurred included respiratory complications (such as ARDS and secondary bacterial infections), cardiac (such as myocarditis, acute coronary syndrome, and arrhythmic), and renal complications (such as oliguria and decreased serum creatinine) monitor.

Using a checklist, data are collected separately or electronically through a web-based program by trained staff. After discharge or death of the patients, data are extracted from their medical records as well as checklists by doctors, nurses, and researchers, and enter into this web-based system. Similar to the COVID-19 registry system developed in Shiraz,[21] patients and their families are monitored during the hospitalization and one month later for vital signs, readmission, and drugs side effects. In addition, as mentioned for the COVID-19 registry system of Shiraz,[21] the author noted that due to the unknown nature of the disease, guidelines and protocols may change during the study. Therefore, a committee of experts continuously monitors national recommendations, data collection issues, and data entry accuracy. Retrospective data recording is one of the disadvantages of this system. However, using pre-designed checklists reduces bias and missing the data.

Finally, the authors mentioned the following advantages for this system: (1) identifying characteristics, underlying diseases, and previous risk factors of patients; (2) assessing the outcomes and better understanding of the risk factors associated with adverse events; (3) evaluating changes in the laboratory findings and their association with the poor outcomes; (4) evaluating and comparing different treatment strategies as well as their efficacy and safety; and (5) creating a platform for further clinical trial studies.

An electronic web-based registry system for COVID-19 with the support of Ilam University of Medical Sciences was designed and developed by Kazemi-Arpanahi et al.[23] According to the information provided in their report, it seems that this system is more accurately designed compared to the aforementioned systems. As mentioned by the authors, initially, they were intended to record essential data and having a valid template in this registry. Then, in the second phase, the system was designed on a web-based platform. To identify essential data, first, an extensive review was performed on various medical databases, including Web of Science, Science Direct, Embase, Scopus, Cochrane, PubMed, and Google Scholar using the definite English keywords. Finally, 18 articles were selected. A checklist was then designed, whose validity was assessed by five experts using a Likert scale to determine the degree of importance of each data ('very important' to 'not very important). The test-retest was utilized to determine its reliability. The initial content was validated during two rounds of Delphi by a group of multidisciplinary specialists from hospitals affiliated with Ilam University of Medical Sciences. Weight was determined for each data and the degree of agreement for each data was calculated. Finally, after deleting 31 variables, 30 variables were selected for the non-clinical subgroup and 4 classes with 26 variables were selected for the clinical subgroup. It is noteworthy that the authors specified the type of each data (Integer, Binary, Categorical, String, and Date). The subclinical data subgroup includes the following: sociodemographic, identifier, and patients' disposition. The clinical data subgroup includes the following: diagnosis, exposure, clinical examination, medical and diagnostic procedures.

The authors noted that the main goal of developing the platform was increasing access to the data and being user-friendliness, to speed up the reporting of COVID-19 data. Moreover, users can do a specific search on the database of the system and obtain daily statistics and multimedia instructions. Access to this system is possible for the registered members; so that each user has a unique password and username to log in. The possibility of contacting the managers of the system and providing useful news about the disease (such as prevention, self-care, and medical information) are other features of the system. Another advantage of the system is the auto-rejection of incorrect values and out-of-range data. Furthermore, it has been attempted to avoid manual data entry as much as possible. They stated that this is a comprehensive registry of COVID-19 and can provide an in-depth description of specific patient groups instead of providing epidemiological data. In this article, the authors showed some figures from a general overview of this registry, which similar articles did not provide. The weaknesses of this study include not reporting of the target group, duration of patients' follow-up, and quality assurance. In addition, the authors did not mention the algorithm of patient care. Similar to the study conducted by Akbari et al,[21] this study also did not provide any statistical reports of the registered patients.

Discussion

Studies conducted based on well-designed and well-completed registries provide a more realistic overview of clinical procedures, patients' outcomes, safety, efficacy, and effectiveness. Meanwhile, they support the decision-making process and evidence-based design.[24] Add to this, the quality of clinical registries can be limited by the lack of unreliable data entry. On the other hand, manual data entry is time-consuming and prone to documentation errors (such as inaccuracies and omissions).[25,26] Another important feature for any registry is the ability to interact with other health information systems that can be useful to prevent duplicate data entry[23,27]; therefore, data coordination, uniform data definition, and uniform capture process of each item are of crucial importance.[28,29]

In this review, the articles that described the COVID-19 electronic registry systems designed and launched in Iran were assessed. Due to the ambiguities around the COVID-19 and contradictory recommendations, there is a need to design and set up an electronic patient registration system. On the other hand, considering the differences between various registry systems specially designed for COVID-19, including using various algorithms for patient care, differences in target groups, using different variables, it is recommended to design and develop a single web-based registry system by the MoHME to register and follow up patients with COVID-19, so that the data of these patients can be recorded nationally and uniformly in all health care centers. Registration can either be retrospective or prospective.[30] Having a single uniform system, in addition to clarifying various aspects of the disease such as patients' characteristics, risk factors, laboratory findings, effective treatments, prognosis, and the trend of the disease, provides the possibility of conducting comprehensive and holistic epidemiological studies in the country. What is more, using a uniform system provides the ability to compare provinces and cities. Another advantage of such systems includes investigating specific groups (such as patients with cancer, cardiovascular disease, diabetes, congenital diseases, pregnant women, etc). Also, by launching a single system and linking it to other health information systems, in addition to increasing research capacity, the educational capacity will expand. Other benefits of such systems include the possibility of evaluating the short-term and long-term outcomes of patients using different variables as well as evaluating, comparing, and improving the quality of care.

Review Highlights

What Is Already Known?

Since the beginning of the COVID-19 epidemic in Iran, several electronic registration systems are designed and launched to record the data of infected patients. In this study, we investigated the articles that described the COVID-19 electronic registry systems in Iran.

What Does This Study Add?

It was found that various registry systems were different in the used algorithms for patient care, target population, and defined variables. Hence, it is recommended to develop a single web-based registry system by the Iran Ministry of Health and Medical Education to register and follow up the patients with COVID-19.

Conclusion

Considering the differences between various registry systems designed for COVID-19 in Iran, it is recommended to develop a single web-based registry system by MoHME of Iran to register and follow up the patients with COVID-19.

Authors' Contributions

RSM contributed to supervision, conception, design, acquisition of data, and writing up the manuscript. HS contributed to the conception, acquisition of data, and writing the manuscript. RSM contributed to the acquisition of data and writing up the manuscript. MS contributed to the acquisition of data and writing up the manuscript. RS contributed to the acquisition of data and writing up the manuscript. MM contributed to the acquisition of data and writing up the manuscript. All authors critically reviewed the manuscript before final submission and approved it.

Conflict of Interest Disclosures

The authors declared no conflict of interest.

Ethical Approval

Not applicable.s

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