Basic information requirements for designing COVID-19 disease registration system

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Abstract: Collecting data related to COVID-19 disease can significantly impact the management of this pandemic. One of the tools that can be helpful in controlling this disease is developing registry. This study aimed to determine the technical and data requirements of the registry for COVID-19. Databases with keywords related to 'COVID-19' and 'registry' were searched. The existing registries in COVID-19 in Iran and other countries were examined. To finalise the data elements, focus group sessions were held with experts. Thirteen main data classes were identified: demographic information, critical dates, type of sample, patient condition, signs and symptoms, history of smoking and consuming narcotics, history of drugs consumption, imaging finding, differential diagnoses of a severe respiratory disease syndrome,

underlying conditions, complications of the disease, respiratory support and discharge outcomes. Determining data requirements is the first step in developing a registry that can create a standard infrastructure for consistent data collection.

Keywords: registry; data requirement; COVID-19; focus group; minimum dataset; MDS.

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1 Introduction

On 29 December 2019, hospital physicians in Wuhan, China, noticed unusual pneumonia cases (Mani et al., 2020). A new emerging virus is classified as an RNA virus that belongs to the coronaviruses' family, mostly have been led to respiratory tract infections (Yang et al., 2020). nCoV-2019 infection is a respiratory infection associated with a new, unknown coronavirus that has emerged as a human-animal transmissible virus (Tanne et al., 2020). The virus may have mutated or adapted to cause disease in humans. Thus, the outbreak of COVID-19 began in China, and all countries became involved in this global pandemic (Isaifan, 2020). On 11 March 2020, Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2), the virus causes coronavirus disease 2019 (COVID-19) was declared a universal pandemic by the World Health Organization (Cornejo-Pareja et al., 2020). The number of infected patients worldwide is rising dramatically every day and leads to many people's quarantine and the closure of industries (Chakraborty and Maity, 2020). Due to the novel and unknown nature of new coronavirus disease, the

world faces particular challenges and difficulties in controlling and surveillance the disease (Uğur and Akbıyık, 2020). All the scientists and researchers in the world are trying to fight and face this new outbreak by collecting real-time information about infected patients. Given that the burden of COVID-19 disease is significant and considerable, the researchers decided to apply data infrastructure and information technology to enhance efficient research, timely treatment, and disease monitoring and control (Mohammadzadeh et al., 2020a). Systematic registration of diseases, or so-called registry, is an organised system for collecting clinical data to assess the consequences of a particular disease, condition, or exposure in a defined population and serve predetermined scientific, clinical, or political purposes (Akazawa et al., 2018). The collected data, data collection methods, the created reports, and their use vary according to the registry type. Registries may also differ by purpose, location, level of coverage, and type of organisation (Kazemi-Arpanahi et al., 2020). Clinical registries possess an immense standard potential for tracking the clinical outcomes, comparing the efficacy of numerous interventions, describing disease natural progression, evidence-oriented therapy, and post-marketing drug surveillance (Javanmard et al., 2020; Kodra et al., 2017). Furthermore, this system is an ideal tool for clinical study when improving health care quality is essential. In many diseases, registry systems are used for epidemiological studies, preliminary studies, risk modelling and other purposes (Sabbaghi et al., 2020).

Providing more appropriate and effective care, facilitating rapid and accurate diagnoses, faster and more extensive access to the patient's medical history, reducing the risk of adverse drug effects or unsatisfactory response to the treatment, and improving productivity and managerial effectiveness are among the possible benefits of using the registry system for COVID-19 infection (Dandachi et al., 2020). COVID-19 registration system is considered as a data source for standardising a comprehensive data set on the unknown dimensions of the disease (Javanmard et al., 2020); in other words, based on the data point recorded in it, the severity of the disease, prognostic factors, effectiveness and complications of treatment protocols, prediction of survival, prevalence and incidence of the disease in the country, clinical phenotype and the possibility of accurate monitoring can be determined (Kodra et al., 2017; Dandachi et al., 2020).

Although establishing and implementing such a system may seem expensive and complicated, it reduces the burden of disease and its consequences, like mortality, and is cost-effective in the future. The first step in designing a registry system is to determine the system's data requirements that have been addressed in this research.

2 Material and methods

This descriptive cross-sectional study was conducted in 2020. This study tried to examine the technical and clinical data requirements related to developing a registry for COVID-19 outbreak. In order to determine the clinical and technical data requirements, a literature review was done to identify national and international systems and scientific literature related to COVID-19. This scientific review aimed to identify the administrative, clinical, and technical requirements of registries designed in this field. First, Scopus, Medline (through PubMed), Web of Science, IEEE, and Google Scholar databases were searched, and also Iranian databases, including IranMedex, Magiran, and SID, were examined for studies in Persian. For this purpose, we used a combination of keywords (('registries' [mesh] OR 'registry system' OR 'disease registry' OR 'clinical

registry' OR 'clinical data registry' OR 'patient registry' OR 'population registry') AND ('2019 novel coronavirus disease' OR 'COVID19' OR 'COVID-19 pandemic' OR 'SARS-CoV-2 infection' OR 'COVID-19 virus disease' OR '2019 novel coronavirus infection' OR 'coronavirus disease 2019' OR '2019-nCoV disease' OR 'novel coronavirus 2019 disease')). In the next step, the systems and registries used in Iran and other countries to record the data of COVID-19 patients were investigated. The systems that used in Iran to record data related to COVID-19 patients were 'medical care monitoring centre' (MCMC) and 'syndromic surveillance system of infectious diseases' (ISSS). MCMC system has been created to organise medical services monitoring through effective and efficient communication, accelerating services, improving the quality of services, improving processes, and integrating management. This system has been developed in Iran by the Emergency Organization and has a purpose beyond recording the information of COVID-19 patients and is not specific to this disease. The primary purpose of ISSS system is the early detection and reporting of community-based epidemics. ISSS system, like MCMC, is not designed to manage COVID-19 disease. To review the technical requirements related to the development of registries, all sources reviewed these requirements were examined separately in the mentioned databases. Based on an investigation of scientific literature and existing registries in the field of COVID-19, the initial data elements were identified. To finalise the technical requirements, focus group sessions were held with six experts in health information technology, and medical informatics. Another focus group session was designed to determine the clinical and administrative data requirements with the physicians, nurses, health information management, and medical informatics experts (six experts).

3 Results

Based on conducted surveys from experts and investigating two national systems, MCMC and ISSS, data elements and requirements were determined for developing COVID-19 registry system. Finally, thirteen critical data elements were identified for designing the mentioned registry system that includes as follow:

- 1 demographic information
- 2 critical dates
- 3 type of sample
- 4 patient condition
- 5 signs and symptoms
- 6 history of smoking and consuming narcotics
- 7 history of drugs consumption
- 8 imaging finding
- 9 differential diagnoses of a severe respiratory disease syndrome
- 10 underlying conditions
- 11 complications of the disease

12 respiratory support

13 discharge outcomes.

As can be seen in Table 1, thirteen main items have sub-items that are listed in detail. Notably, clinical registries are big databases comprising information about individuals affected by a specific condition; therefore, Figure 1 shows the specific features of the COVID-19 (specific requirements) disease registration system. In this Figure, the title of the disease registration program, the population under study, the registration's geographical scope, the main objectives of the registration, the definition of the disease, the method of diagnosis and the type of registration are given. In the following, Figure 2 presents the main functions of the disease registry system; the significant functions of COVID-19 registry are to provide multiple views of information for various people.

 Table 1
 Main information elements for designing coronavirus disease (COVID-19) registry system

	1 Demogra	aphic information			
First/last name	National ID	Gender	Father's Name		
Nationality	Age (If it is less than one year, mention it in the month)	Province of residence	City of residence		
Phone number	Address	Birth date	-		
	2 Critical dates				
Admission date	Admission time	Hospitalisation date	Isolation date		
Sample submission date	Sampling date	-	-		
3 Type of samples (items selection)					
Throat swab	Noise swab	Cerebrospinal fluid (CSF)	Necropsy		
Throat gargle	Tracheal tube suction	Bronchoalveolar lavage (BAL)	Sputum induction		
4 Patient condition					
How to go to the medical centre	COVID-19 test result	Result of CT-scan of lungs	Previous history of COVID-19 infection		
History of contact with a patient with COVID-19	Travel history in the last seven days	Bird contact history	Animal contact history		
History of contact with foreign travellers	Number of breaths	SPO2 rate (percentage)	Temperature rate		
Intubation	-	-	-		
	5 Signs and sym	ptoms (items selection)			
	5.1 Influenza	a-like key symptoms			
Fever over 38 degrees	Sore throat	Cough	-		
	5.2 Symptoms of the lower respiratory tract				
Shortness of breath Bloody sputum	Chest pain	External pharynx -	Difficult breathing -		

 Table 1
 Main information elements for designing coronavirus disease (COVID-19) registry system (continued)

5.3 Cardiovascular symptoms					
Chest pain	Low blood pressure	-			
- Chest pain	5.4 Nerves systems symptoms				
Vertigo	Drowsiness	Convulsion	Loss of consciousness		
5.5 Auxiliary symptoms					
Loss or reduction of smell sense	Loss or reduction of taste sense	Muscular pain	eye redness		
Headache	Vomiting	Diarrhoea	Stomach ache		
Sneezing	Skin lesions	Joint pain	Anorexia		
Redness of the conjunctiva	Nasal congestion	Paralysis of the limbs	Abnormal hearing		
Bruising of the skin	-	-	-		
-	6 History of smoking	g and consuming narcotics	7		
History of smoking	History of using narcotics	-	-		
	7 History of	drugs consumption			
Long-term use of aspirin	Long-term use of immunosuppressive drugs	chemotherapy	cortisone		
	8 Ima	ging finding			
CRX	Bilateral infiltration	Ground-glass opacities	-		
Chest CT-scan	Bilateral infiltration	Ground-glass opacities	-		
9 Differenti	al diagnoses of severe res	piratory disease syndrome	e (items selection)		
Seasonal flu pneumonia	Diphtheria	Measles	Severe acute respiratory syndrome (SARS)		
Legionella	Pneumonic plague	Human metapneumovirus (HMPV)	Parainfluenza		
Chikungunya	Atypical pneumonia/ mycoplasma	Chlamydia	-		
10 Underlying conditions					
Chronic liver disease	Diabetes mellitus	Blood Disorder	HIV (AIDS)		
Pregnancy	High blood pressure	Asthma	Chronic neurological disorders		
Acquired/ congenital immunodeficiency	Cancer/chemotherapy condition	Chronic kidney disease (CKD)/dialysis condition	Lack or removal of the spleen		
Obesity	Malnutrition	-	-		

 Table 1
 Main information elements for designing coronavirus disease (COVID-19) registry system (continued)

	11 Complicat	ions of the disease			
	11.1 Pulmon	ary complications			
Bronchitis	Primary pneumonia (viral)	Secondary pneumonia (bacterial)	Pulmonary embolism		
Pulmonary edema	Acute respiratory distress syndrome (ARDS)	-	-		
	11.2 Cardio	ac complications			
Myocarditis	Pericarditis myocardial infarction (MI)	Heart failure	-		
Endocarditis	-	-	-		
	11.3 The nervous and central system complications				
Meningitis	Encephalitis	Meningoencephalitis	Cerebral venous sinus thrombosis (CVST)		
Intracranial bleeding	Resistant epilepsy	-	-		
	11.4 Renal/bl	ood complications			
Pyelonephritis (cystitis)	Acute tubular necrosis	Uremia	Bleeding following thrombocytopenia		
Disseminated intravascular coagulation (DIC)	-	-	-		
	12 Respi	ratory support			
Process start date	Process end date	-	-		
	13 discha	urge outcomes			
	13.1 Discharged patient information				
Date of discharge	Condition of discarded patients	-	-		
	13.2 Deceased	patient information			
Death in the hospital	Death in outside of the hospital	Name of the unit where the patient died	-		
Intensive care unit (ICU, CCU, NICU, PICU)	Date of death	-	-		

Figure 1 The specific features of the COVID-19 registration system (see online version for colours)

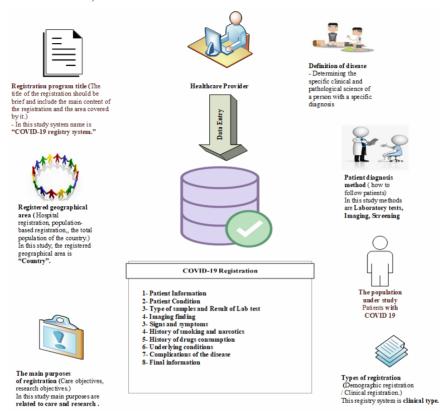
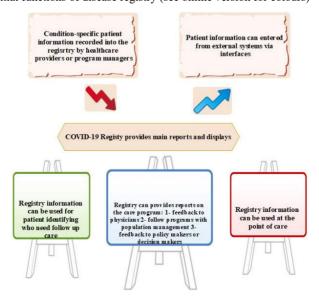


Figure 2 Essential functions of disease registry (see online version for colours)



Based on a run survey of medical informaticians and health information managers, some of the COVID-19 registration system's technical requirements have been identified, which are listed in Table 2. In this table, the external interface requirements of designing a registry system were determined.

 Table 2
 Technical requirements of developing COVID-19 registry

External interface requirements	Specific technical aspects
User interfaces	• The system graphics are such that the user works with it with complete satisfaction and has high graphics.
Hardware interfaces	Several users can use it simultaneously
	• The system must be capable of spatial changes
Software interfaces	Management of the disease registration system
	• The system must be able to determine the level of users' access to information
	• The system must be compatible with the plans of insurance organisations, hospital information systems.
Communications interfaces	• The system must be compatible with the Internet
	• The system can work with the network
	• The system must be able to exchange information with HIS hospital information systems.
	• The standards of exchange, terminology, unit, and uniform coding should be used to record and exchange information.
Database designing	NoSQL: MongoDB, Redis, Casandra
Software designing	Net framework, Vb.net, Microsoft Visual Studio, SQL Server

4 Discussion

This study aimed to determine the data requirements for the COVID-19 disease registry. After investigating the existing systems and expert surveys, thirteen main data classes were identified.

Thirteen main data classes for designing the mentioned registry system were as follows:

- 1 demographic information
- 2 critical dates
- 3 type of sample
- 4 patient condition
- 5 signs and symptoms
- 6 history of smoking and consuming narcotics
- 7 history of drugs consumption

- 8 imaging finding
- 9 differential diagnoses of a severe respiratory disease syndrome
- 10 underlying conditions
- 11 complications of the disease
- 12 respiratory support
- 13 discharge outcomes.

Using registries in the healthcare field can lead to data collection related to diseases in a unified and standard way. By storing health data in the registry, the progress of diseases can be described, and also the quality of health care can be evaluated. The registries can be used to evaluate the cost-effectiveness of the treatments provided (Choinière et al., 2017). Determining the registry's minimum data set and critical requirements is a big step in designing and developing these systems. Designing a registry for epidemics, especially the COVID-19 epidemic, provide a reliable infrastructure for collecting COVID-19 data. With the help of registries in this area, the epidemiological investigation can be facilitated, and policymakers can better plan based on the registries' information and monitor the disease's progress (Kazemi-Arpanahi et al., 2020). Clinical data registry can provide valuable insights to health care providers, health care policymakers, and researchers regarding the characteristics of patients with COVID-19, the treatment patterns used, and the clinical outcomes of these patterns in hospitalised patients (Alger et al., 2020; Mohammadzadeh et al., 2020b).

The data elements identified for the registry in this study were classified into 13 main classes that can generally be divided into administrative and clinical data categories. A study conducted by Shanbehzadeh et al. (2020) determined the minimum data set for the surveillance system in COVID-19 disease. In this study, 11 main classes and 137 fields were determined; the highest number of data elements was related to demographic information with 27 fields and laboratory information with 21 fields. In the present study, 11 fields were related to demographic information, and more emphasis was on patients' clinical data (Shanbehzadeh et al., 2020).

Registry data has been used in the COVID-19 epidemic for various purposes, leading to valuable knowledge creation. In a study by Uribarri et al. (2020), international registry data were used to evaluate the effect of kidney disease on the mortality rate of COVID-19 disease, and it was concluded that these patients had more complications and mortality than other patients. In Spain, a registry has been used to improve knowledge in clinical, prognostic, diagnostic, and therapeutic aspects. This study has yielded valuable results and concluded that one in three patients with COVID-19 manifests respiratory distress, and one in five patients dies (Casas-Rojo et al., 2020). In Denmark, with the help of data recorded in the registry, they examined the mortality rate of patients with COVID-19. They concluded that timely lockdown significantly impacted the infection process, and the mortality rate did not increase (Mills et al., 2020). As mentioned, by collecting structured and unstructured data in the registers, valuable knowledge can be created and provided to policymakers to plan (Hasan et al., 2019).

With the advent of COVID-19 disease and the need to record data, many countries began to create national registries. In Iran, a registry devoted to COVID-19 disease has not been developed, but two systems, MCMC and ISSS, are used to record administrative and clinical data related to COVID-19. Determining data elements and requirements can

be the first and most significant step in establishment of a data registry for COVID-19 disease. It can be used to determine survival estimation, the effectiveness and side effects of drugs used, disease prevalence in different parts of the country, and it can be used as a tool for researchers and policymakers with the purpose of planning (Irie et al., 2020; Kazemi-Arpanahi et al., 2019).

The strength of this study was the methods applied to determine the data elements. In this study, the scientific literature was first reviewed, and all the data elements required for COVID-19 patients were identified. In the next step, the existing systems and registries in COVID-19 disease were examined, which led to the identification of more data elements. Finally, based on a survey of experts, the necessary data elements needed to monitor patients were identified and confirmed.

5 Conclusions

This study represents data requirements and essential elements for developing a Coronavirus disease (COVID-19) registry system. Accessing this registry system led to that health care providers can call patients infected new emerged Coronavirus disease 2019 with specific needs, receive immediate feedback on their performance, deliver planned cares, and establish reminder systems. By applying this disease registry, the healthcare team can follow their patients individually and by population subset, allowing them to provide proactive care and treatment to individual patients or groups of similar patients. Therefore, remarkably the registry of COVID-19 has a significant role in improving medical knowledge, creating a platform for research, and increasing the quality of health services provided to patients. Meanwhile, this study's results can encourage researchers to use the registry system in the care of patients, forecasting prevalence or incidence rate and screening field; it can help the decision makers and policymakers make better decision regarding managing and preventing the COVID-19 in the countries.

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Availability of data and material

All data generated or analysed during this study are included in this published article.

Compliance with ethical standards

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