Designing the Coronary Artery Disease Registry with Data Management Processes Approach: A Comparative Systematic Review in Selected Registries

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ARTICLE INFO	ABSTRACT
	Context: The use of registries to Coronary Artery Disease (CAD) data management plays an important role in the improvement of healthcare processes and reduction of outcomes for patients and healthcare providers. The present study aimed to compare the data management processes of CAD registries in the selected countries. **Evidence Acquisition:** This review study was conducted comparatively in 2019. After selecting countries based on some criteria, the required data were collected by searching valid databases, more useful search engines, and related websites to CAD registries for the selected countries as well as by sending E-mails containing a data extraction form to the related organizations. **Results:** Totally, five registries were chosen in the selected countries as follows: CADOSA (Australia), APPROACH (Canada), START (Italy), CLARIFY (Spain), and GWTG-CAD (US). The results showed that 60% of the selected registries made use of the electronic case report form for data gathering. The main data elements included demographic and general information, risk factors, vital sings, medication, laboratory tests results, examination results, ECG results, invasive measures and interventions, patient's status on discharge, results of follow-ups, and post-discharge outcomes. **Conclusion:** Developing CAD registries based on the data management principles provides the context to conduct cohort studies with very low costs. With regard to the study results, attention should be paid to data management processes, include data gathering, data processing, and information distribution, in development of CAD registries.

1. Context

Coronary Artery Disease (CAD) is the main cause of mortality in middle- and high-income countries (1, 2). It happens due to the tightening, damaging, or narrowing of the arteries that supply blood, O2, and nutrients to the heart muscle (3). This occurs due to the formation of cholesterol and other materials called plaque, a waxy substance, on the inner walls of the vessels, which is called atherosclerosis (2-6). The stenosis in coronary arteries is one of the CAD symptoms, which could lead to cardiovascular accident and ultimately death (7, 8). Determined diagnosis of CAD is done via angiography. Additionally, the coronary arteries can be unblocked by using medications, angioplasty, or coronary artery bypass grafting (9, 10). Based on the World Health Organization's (WHO) report, heart diseases are one of the main causes of death all over the world, and more than 80% of these deaths are caused by CAD (11, 12).

In developed countries, important measures are being taken to reduce the complications of CAD and improve healthcare delivery, including nutrition control, improvement of living conditions, medication treatment, and data management (13-16). Registries as valuable data management tools (15), for CAD also play a pivotal role in reducing the disease complications through improving the provision of healthcare services and patients monitoring and follow-up (17, 18). Disease registry refers to the continuous and

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systematic collection of information from all individuals in a specific population for whom a specific disease or health event has been diagnosed (19). Registries are the main tool for managing patient data by following clinical guidelines and standards and reducing the costs of healthcare services, which are used to improve patient care processes (15, 20). Registry programs aim at regular collection of information about a specific health status in a particular community or hospital and analyzing and interpreting the data to monitor the status of the defined population (15).

Disease registries are generally classified into two categories, including hospital-based registries and population-based registries (15). Hospital-based registries are very effective in monitoring the treatment process and improving the quality of the provided healthcare services to patients (21). In many countries, hospital-based registries are used for policymaking and service planning, which have become an integral part of the hospitals' quality control programs and play a key role in the countries' healthcare systems. The use of hospital-based registries for CAD helps identify and manage the disease, increase knowledge and awareness, improve the knowledge of healthcare providers, and evaluate the quality of care (22-24). In the recent decades, many registries have been designed in the area of CAD.

PRORECAD is a multi-centered registry for CAD launched in Italy in 2003. The main aim of this registry is to assess the CT Coronary Angiography (CTCA) diagnosis value based on the retrospectively collected data. This registry is active in patient follow-up as well as in reporting and reviewing patient death (25). The CRAGAS registry also operated as a multi-centered hospital-based registry (with 15 hospitals) in Europe for ten years between 2002 and 2012. It aimed at long-term follow-up of surgical outcomes for patients suffering from the disease aged between 18 and 50 years (26).

The developed registries in the field of CAD in developed countries have become an emerging tool in healthcare data management and support, and have an important position in prevention, treatment, and follow-up of diseases. However, there is little experience and documentation on how to design, develop, and make use of registries to manage CAD data. Therefore, the present study aims to review and compare data management processes in CAD registries in the selected countries in order to identify the experiences and key features in designing and developing CAD registries.

2. Evidence Acquisition

This comparative review study was carried out in 2019. In order to select the developed countries in this field, the following steps were taken:

1. European Union countries (28 countries), North America (two countries), and Australia were selected as the developed countries in the field of health information (27, 28).

2. In order to select the developed countries in the field of CAD registries, the search was conducted using the following keywords: (("registry" OR "registri*" OR "data management" OR "information management" OR "surveillance system" OR "monitoring system") AND ("coronary artery disease" OR "coronary heart disease" OR "ischemic heart disease" OR "acute coronary syndrome" OR "CAD" OR "CHD" OR "STEMI" OR "non STEMI" OR "ACS")), without time limitation.

3. The searches were done in PubMed, Scopus, and Google Scholar databases. The websites of the selected registries were searched and reviewed, as well. In order to select the related registries, the following criteria were taken into consideration:

a. The selected registry should be ongoing.

b. The selected registry should have the complete registry processes, including case finding, data gathering, abstracting, follow-up, reporting, and data quality control (15).

c. The selected registry should be multi-central.

d. The registry population should more than 1000 cases.

e. More than a year should be passed from its beginning.

4. According to the step 3 criteria, five registries from five countries were selected, which have been presented in Figure 1.

After the selection of the related registries, use was made of a data extraction form designed based on the study objectives. The mentioned form contained three main parts, including the general information of registries, information related to CAD data management, and other
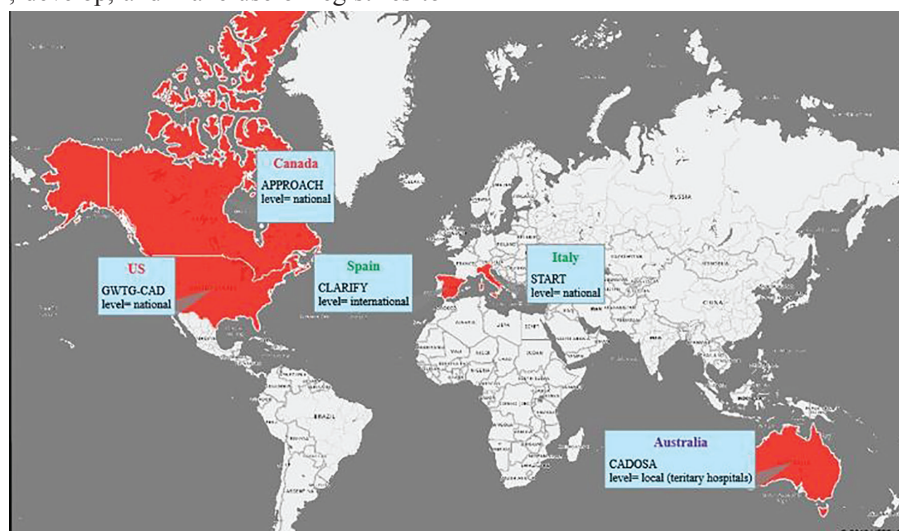
Figure 1. The Locations of the Selected Registries

features and information about the selected registries. As data management has three parts including data gathering, data processing, and information distribution, these three indicators were also taken into consideration in the data collection from. The collected data were abstracted and reported in comparative tables based on the study objectives.

3. Results

After the application of the inclusion criteria, five registries were selected whose geographical locations have been depicted in Figure 1.

The features of the selected registries in the six categories, including starting year, data exchange platform, data gathering tools, time to update, interoperability with other electronic healthcare systems, and main indicators, have been presented in Table 1.

The main data elements of the registries in the 10 main categories have been presented comparatively in Table 2. Accordingly, START registry had all the main data elements.

The information distribution conditions in the selected CAD registries and their comparison have been shown in Table 3.

4. Discussion

CAD is the main cause of death in many countries all over the world and has caused lots of damages. However, none of the selected registries were in Asian, African, and South American countries with a high percentage of the world's population. In order to deal with CAD successfully, CAD registries have to be designed and developed based on the specific needs of different regions. In the present study, the selected countries had specific knowledge management processes, including data gathering, data processing, and

Table 1. The Features of the Reviewed Registries

	Registry Name	Starting Year	Data Exchange Platform	Data Gathering Tools	Data Update Time	Exchangeability with other Electronic Systems	Main Indicators
1	CADOSA	2011	Paper-based and web-based *	A uniform data form for all hospitals	1 and 12 months	EMR	Cause of death, MI, readmission, and quality of data
2	APPROACH	1995	Paper-based and web-based *	Electronic case report form	1, 3, and 5 years	Connection to electronic health records and other monitoring systems	Number of patients, CABG, PCI, and cardiac catheterization
3	START	2011	Web-based	National standard electronic case report form	12 months	- **	Health services evaluation and patients' quality of life
4	CLARIFY	2009	Web-based	International electronic case report form	Annually	-	The most important indicators of diseases and therapeutic and surgical operations
5	GWTG-CAD	2000	Web-based	Standard on-line form	Alternate	-	Related indicators to AMI, CAD, and chest pain

These registries used both platforms. ** No information found

Table 2. The Main Data Elements of the Selected Registries

Data Elements		Registry				
		CADOSA	APPROACH	START	CLARIFY	GWTG-CAD
1	Demographic and general information	✓	✓	✓	✓	✓
2	Risk factors and family history	✓	✓	✓	✓	✓
3	Vital signs	✓	✓	✓	✓	✓
4	Medication	-	-	✓	✓	-
5	Results of laboratory tests	✓	✓	-	✓	-
6	Examination results	✓	-	✓	-	✓
7	ECG results	✓	✓	✓	✓	✓
8	Non-invasive and invasive measures and interventions	-	-	✓	✓	-
9	Patient's status on discharge	✓	✓	✓	✓	✓
10	Results of follow-ups and post-discharge outcomes	✓	-	✓	-	✓

Table 3. Information Distribution in the Reviewed Registries

	Types of Reports	The Level of Reports Application	Related Organizations
CADOSA	Reports, articles	Tertiary hospitals	Registry strategic committee, centralized clinical data manager
APPROACH	International and national journals, report for organizations	National	Hospital administrators, health officials, healthcare administrators
START	Reports for ANMCO, articles	National	ANMCO
CLARIFY	Reports, articles	International	Registry strategic committee, the ministries of health of the related countries
GWTG-CAD	Performance feedback reports, articles	National	Some private countries

information distribution, in their CAD registries. Yet, CLARIFY was more complete compared to other reviewed registries in terms of knowledge management processes. This registry is an international one with 50 member countries and is more comprehensive with respect to data elements, processing indicators, and information distribution level (22, 29-32). However, because of its internationality, this registry may not be able to cover all the specific information needed for a country, region, or even hospital.

Due to the importance of web-based registries in the ease of access to information for different managerial and therapeutic purposes, three of the selected registries made use of web-based data exchange platforms (22, 29-31, 33-35), while the two other registries utilized hybrid (web-based and paper-based) platforms for data sharing (36-39). The use of web-based platforms prevents data processing experts from re-working and reduces the loss of resources and time needed for data collection. Napier et al. designed a registry for management of familial hyperglycemia data and concluded that it facilitated the collection and exchange of data and provided the basis for improving healthcare services (40). Tabrizi et al. also reviewed three main registries about cardiac catheterization, including NCDR, MIG, and EHS-PCI (CARDS), and reported that all registries were web-based (41).

The reviewed registers made use of standard forms in data gathering (case report form) regardless of their scopes and purposes (29, 30, 35, 36, 39). The use of uniform data gathering forms in registries reduces the time required for data gathering by staff and prevents the collection of extra and irrelevant data. The results of the related studies also showed that the use of standard and uniform data gathering and abstracting forms for a disease registry enhanced data quality, especially data completeness and data accuracy (42, 43). The results of investigation of the main data elements of the CAD registries can be used by system designers and developers.

The results of the present study showed interoperability with patients' electronic health records in only two registries (36, 44). The interoperability between a registry and electronic health records helps data accessibility (45, 46). Despite the many differences between the registries and electronic health records in producing evidences, public reports, and quality improvements (47), it seems that it is time to consider this feature seriously in the development of the CAD registry as well as in other diseases registries.

Data processing is one of the main dimensions of data management processes. The CLARIFY registry had all the main indicators and more data processing capabilities compared to other registries. Generally, considering the required indicators when designing the registries could improve their processing capabilities. Data processing, in turn, can help improve healthcare quality (48). Rajaram et al. also described the effectiveness of using a registry in presentation of indicators (49). Therefore, selection of appropriate indicators is a key component that should be taken into account in designing and developing registries.

Information distribution is the final step in the data management processes. The manner and quality of information distribution depend on the type of the collected data and the used processing indicators. However, different reports have been published in registries based on their purposes and activity levels. In addition to distributing information through scientific articles, the selected registries distribute information to specific organizations and centers based on specific mechanisms. In the START registry, the reports are regularly published and managed by ANMCO and are presented to various centers and organizations. A significant number of articles are also published from the registry reports (29, 33). Overall, one of the most important components in design and development of CAD registries is the ability to distribute credible, functional, and relevant information appropriated to the needs of the concerned organizations, which should be addressed carefully by system developers.

5. Conclusion

Designing and developing CAD registries need attention to be paid to data management processes, including data gathering, data processing, and information distribution. In fact, it should be considered as a key roadmap for system development by developers and stakeholders. These processes have been considered in all the reviewed registries based on their specific objectives, causing them to acquire useful experiences. The present study made attempts to identify and report these experiences. Consequently, the results could be helpful in designing and developing CAD registries.

The results of the present study suggested the use of web-based platforms in the data gathering process due to their high capacity of data transfer. Additionally, registries should apply uniform data gathering and abstracting forms to improve data integrity. Considering the selection of relevant, appropriate, and standardized data elements to the relevant requirements, special attention should be paid to the selection of data elements in development of CAD registries. To improve the processing capability of the registries, the key indicators should be taken into consideration through identifying the main stakeholders' data requirements. In addition, understanding of reported needs and information that should be shared between different bodies is another key determinant when developing registries.

Authors' Contribution

AG, RR, and HE designed the study, RR and HE supervised the study, AG and RR prepared the preliminary draft of the manuscript, MP and MV-A checked the clinical and technical aspects of the manuscript, RR, HE, and AG revised the manuscript critically, all authors read and approved the final draft of the manuscript.

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