

Report

Diseases and Health Outcomes Registry Systems in I.R. Iran: Successful Initiative to Improve Public Health Programs, Quality of Care, and Biomedical Research

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Abstract

Registration systems for diseases and other health outcomes provide important resource for biomedical research, as well as tools for public health surveillance and improvement of quality of care. The Ministry of Health and Medical Education (MOHME) of Iran launched a national program to establish registration systems for different diseases and health outcomes. Based on the national program, we organized several workshops and training programs and disseminated the concepts and knowledge of the registration systems. Following a call for proposals, we received 100 applications and after thorough evaluation and corrections by the principal investigators, we approved and granted about 80 registries for three years. Having strong steering committee, committed executive and scientific group, establishing national and international collaboration, stating clear objectives, applying feasible software, and considering stable financing were key components for a successful registry and were considered in the evaluation processes. We paid particulate attention to non-communicable diseases, which constitute an emerging public health problem. We prioritized establishment of regional population-based cancer registries (PBCRs) in 10 provinces in collaboration with the International Agency for Research on Cancer. This initiative was successful and registry programs became popular among researchers and research centers and created several national and international collaborations in different areas to answer important public health and clinical questions. In this paper, we report the details of the program and list of registries that were granted in the first round. Keywords: Biomedical research, Diseases and health outcome registry, Registration system, Public health

Cite this article as: Mojarrab S, Rafei A, Akhondzadeh S, Jeddian A, Jafarpour M, et al. Diseases and health outcomes registry systems in I.R. Iran: successful initiative to improve public health programs, quality of care, and biomedical research. Arch Iran Med. 2017;20(11):296–303.

Published Online November 1, 2017

Introduction

According to the World Health Organization (WHO), patient registry is “a file of documents containing uniform information about individual persons, collected in a systematic and comprehensive way, in order to serve a pre-determined scientific, clinical or policy purpose.”¹ Collected information is used for assessment of specified events in the target population that could be defined by special diseases, conditions, or exposures for scientific, clinical, or policy purposes.² Figure 1 illustrates the core and supporting process of a disease registry system. The core process for a registry includes detection of patients and registration of the information, data cleaning and removal of duplicates, applying quality control measures, data analyses, and preparing regular reports. These processes need to be supported by several other supporting environments and infrastructure, including stable financial support, information technology (i.e., registry software), trained registrars and other related staff, and proper basis and infrastructure to implements

the core process (Figure 1). Patient registries apply observational study methods for evaluation of the defined objectives.³ The advantages of registry-based include addressing a large study size and diverse group of patients in several treatment centers. In addition, they have no restrictions for evaluation of concurrent treatments and co-morbidities, and consider an extended time-frame in their evaluation and provide evidence for effectiveness of treatments in the real world.^{4,5} Data from registries may generate several hypotheses that can be tested by clinical trials and other analytical methods.

Policy makers apply the data from patient registries to understand the etiology of diseases in the target population, evaluate treatments pattern, conduct safety surveillance and study different outcomes to demonstrate the value of the interventions.² The intervention might be a drug, vaccine or therapeutic or surgical procedure as well as changes in lifestyle and physical environment. Because patient registries are used for scientific research, they are interested in collecting and storing biological

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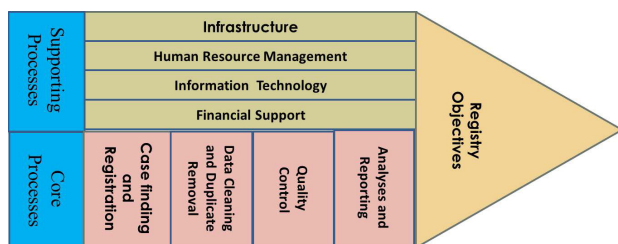


Figure 1. Schematic Introduction of the Core and Supporting Process of a Registry Program.

samples and establishing biobanks to assay the genetic origin of diseases or measure other biological indicators. Research projects can also be planned and managed using the data from patient registries.

The earliest example of a disease registry in the world was the National Leprosy Register that was set up in Norway in 1856 and registered 8000 patients until 1973.⁶ Cancer Registry is one of the oldest registries that was implemented by several countries, including Massachusetts, USA (in 1927), Britain (in 1930), Denmark (in 1942), France (in 1943), and Finland and Norway (in 1952).^{7,8} The International Agency for Research on Cancer (IARC)⁹ publishes the results from different cancer registries in a monograph called “Cancer Incidence in Five Continents (CI5).” The 10th volume of CI5 published results from 290 population-based cancer registries (PBCRs) from 68 countries and 424 populations in 2013.¹⁰

The number of disease registers has increased considerably from 1950s in the world. The reasons for this increase are growing concern about the impact of chronic diseases in the population. Advances in the epidemiological and statistical methods, and improvement in the information technology for handling large amounts of data were important elements for development of patient registries worldwide. Nowadays, hospitals, laboratories, and public health sectors use computer and different software for administrative purposes and archiving patient data and information about the services provided during different visits. This has improved access to data and feasibility of developing different disease registries. For instance, in the United States, the SEER program managed to publish the results of cancer registries for 16 states until 1998.¹¹ Coverage of SEER program was 30% up to 1998 and the data from this program was used to estimate cancer incidence in the United States. However, the Centers for Disease Control and Prevention (CDC) took advantage of the SEER program experience and advances in the information technology and extended this program to all states in the United States and increased the coverage of the PBCR to about 100%.¹²

In Iran, the earliest report of registries pertained to

cancer registry.¹³ Other examples of registries include causes of death registry (1998),¹⁴ registry of primary immunodeficiency diseases (PID) (1997),¹⁵ and registry of congenital abnormalities (2000).¹⁶ These registries were mostly supported by the government and universities and their purpose was public health surveillance and research.

In 2014, the deputy of research in the Ministry of Health and Medical Education (MOHME) of Iran decided to establish registry systems for different diseases and health outcomes. After a formal call and evaluation of proposals, more than 50 registries from different institutions were approved and received financial support to initiate registries in the regional or national level. In this paper, we report the activities and progress of the national program for registry of diseases and health outcomes.

Objectives

Then main objectives of the national program for establishment of registry systems for diseases and health outcomes were developing high standard registries in the country. The specific objectives were to (1) strengthen capacities and infrastructures for patient registry; (2) provide financial support for the diseases with higher priorities; (3) run workshops and training programs for diseases registry; (4) increase national and international collaboration for disease registry; (5) establish a monitoring system for the approved registries; (6) support development of the registration software; (7) support establishment of biobank of the patients registry programs; and (8) link the registry programs to the health system for improvement of quality of care and public health interventions.

The national program was under direct supervision of the deputy of health. An office was established as the secretariat for the program. However, the program relied mainly on the intuitional capacities that were available in the medical universities, hospitals, and research centers. In fact, this program fed the research centers that were established in the country during the last decade.¹⁷

Major Activities

To meet the objectives, the following steps were taken:

- Developing proposal template to receive applications from the research centers, and individual researchers working in the medical universities.
- Organizing a series of workshops and training programs to introduce concepts, methods, and standards for establishment and management of a registry.
- Peer reviewing the applications submitted to the secretariat and providing approvals for the registries that met the criteria and standards.

- Providing consultation to the researchers and research experts in the medical universities about the application and strategies for establishment of the registry programs.
- Prioritizing establishment of the PBCRs in at least 10 provinces in collaboration with the International Agency for Research on Cancer.⁹
- Providing 3–4-year grants for the approved applications.
- Developing a monitoring and evaluation and ranking system for medical universities *visa-a-vis* establishment and supporting the registry programs.¹⁷
- Collaboration with the office of statistics and information technology in the MOHME to develop standards and regulations for enhancing the hospital information systems (HISs) and laboratory information systems to meet the needs of registry programs and facilitate data exchange with the registries.
- Organizing the first international conference on registry program to allow managers of the registries to share their experiences and best practices.¹⁸
- Advocacy through presentations about the program in different meetings.

Call for Proposals

We called for proposals to establish registries in the country. We introduced a specific application form that was designed for the registry program and included the following sections: (1) Objectives and justification of the registry, (2) Scope of the registry (national, regional, hospital, etc.), (3) Principal investigators, and steering committee, (4) Thorough literature review, (5) Suggested organizational chart, (6) Case finding and registration procedures, (7) Sample size estimation, (8) Software, (9) Ethical considerations, (10) Follow-up procedure, (11) Time chart, and (12) Budget.

Submitted proposals were reviewed and applications that met our criteria and priorities were selected for financial support. We relied on the institutional capacities and prioritized the applications that were submitted from the research centers and investigators who had reasonable experience in the area of registry. We also encouraged the applicants to seek international collaboration and join the international registry associations and consortiums. We also encouraged multicenter and collaborative programs that involved different universities, research center, hospitals, etc. We provided a guideline for completion of the application form and provided several consultations and feedbacks to the submitted proposals. We approved 80% of the applications and provided initial financial support to the approved registries. We only supported the registration procedures and did not grant the proposals

that included screening process or expensive laboratory tests for detection of patients.

The requirement for an optimal registry program is shown in Figure 2. In fact, all of these requirements were necessary to make sure that a registry will be properly established and maintained.

Population-Based Cancer Registry

The history of cancer registry has been reported elsewhere.¹⁹ In brief, the history of cancer registry in Iran goes back to 1955, when Dr. Habibi from the Cancer Institute of Iran published the first cancer statistics from Iran.¹³ In 1969, the first PBCR was launched in Babol city of Mazandaran province in northern Iran. The highest incidence rate of esophageal cancer in the world was reported from this registry (more than 100 per 100 000).⁹⁻²⁰ In 1968, another cancer registry started its activities in Fars province. However, these efforts were interrupted in the early 1980s due to the revolution and Iran-Iraq war. In 1984, the Parliament passed a bill mandating the report of all tissues “diagnosed or suspected as cancer tissue” to the MOHME. The bill led to establishment of a pathology-based cancer registry program and the results of this initiative were published between 1999–2009. In addition, several parallel registries were launched by medical universities and research centers including Tehran,²¹ Ardabil,²² Gilan,²³ Mazandaran,²³ Golestan,²⁴ Kerman, Semnan,²⁵ East Azerbaijan,²⁶ and Fars (Shiraz).²³ However, none of these registries were sustained for a long time²⁷ and only the PBCR in Golestan province had sustainable activity and managed to reach the international standards; the first report from this registry was published in the 10th edition of IARC monograph “Cancer in Five Continents.”²¹⁰

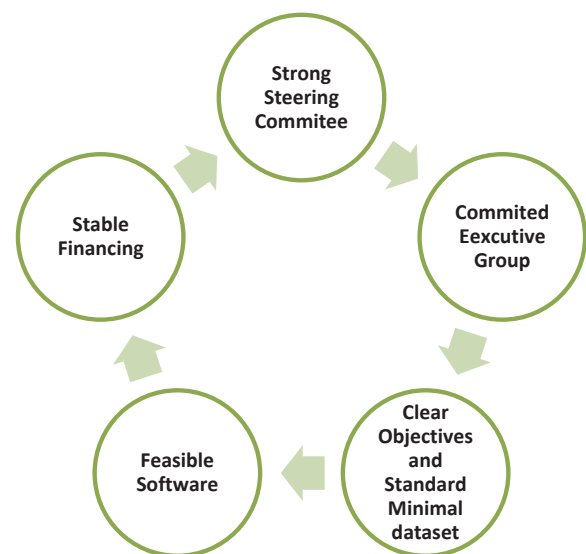


Figure 2. Main Requirements for Successful Registry Program.

In the national registry program, we put particular emphasis on establishment of regional PBCRs in different provinces and established regional PBCR in different part of I.R. Iran, in collaboration with IARC⁹ that provided consultation and technical support. We selected 10 provinces that were located in different parts of Iran, assuming that the results from these provinces would be representative of the entire country. In this program, we established cancer registry offices in each province and assigned a director for the regional cancer registry. CanReg5, an international open-source software developed by IARC, was used as the registry software. We customized the CanReg5 software and added Jalali calendar to facilitate the registration of different dates. The directors and experts of the cancer registry participated in a series of workshops and obtained information about the concepts and methods of PBCR and the CanReg5 software. To overcome the resistance against providing cancer data and collaborating between hospitals, laboratories, public health sectors with the registry personnel, an agreement was signed between the main stakeholders, including deputy of research, deputy of treatment, and deputy of health in the ministry of health to support establishment of PBCRs and also extend the experience to other provinces and increase the coverage of PBCR in the country.

Training and Capacity Building

Because there was little experience about registry program in Iran, training program and organizing workshops were an important part of the national program. We developed a curriculum and lunched 3 national workshops. The topics that were covered in the workshops included (1) Steps to establish and implement a registry, (2) Coding system for diagnosis and procedures (SNOWMED, ICD10, ICD-O3, ...), (3) Data collection methods, software standards for a registry program, (4) Role of information technology and electronic databases in patient registry, (5) Quality control methods, (6) Data linkage and statistical methods, and (7) Ethical considerations in the registry programs.

The first international congress on disease registry was organized by the MOHME and Mashhad University of Medical Sciences.¹⁸ The objectives of the congress were to exchange knowledge and experience between different registry programs. In addition, experience form international programs from Sweden and Belgium was presented and discussed. We also organized training for trainee (TOT) workshops to train representatives from medical universities so that they could organize workshops for the researchers upon their return to their universities.

In addition, we published an online book as educational

material for the registry managers and experts. The website of the national program provided other educational resources, including slides, books, and links to important international resources.¹⁷

Information Technology

The Iranian Integrated Care Electronic Health Record (ICEHR) is a national middleware that creates and manages electronic health record (EHR)²⁶ for Iranian individuals. This national middleware is locally called SEPAS and any patient visits to healthcare facilities are communicated through it. It has a distributed-and service-oriented architecture based on ISO 13606. The basic structure of SEPAS is inspired by openEHR which is also compatible with ISO 13606. The local electronic medical records that are used at healthcare facilities are neither fully compatible with openEHR architecture nor ISO 13606. Thus, the national middleware is also responsible for adapting the non-standard content to standard structure. This national architecture has developed a semi-standard model for local electronic medical records so that they can transfer data to SEPAS more easily. Due to its dual model, SEPAS can communicate, store and maintain various health content types such as laboratory results, medical histories, procedures, admin entry data, etc.²⁸

Some of disease registries in Iran were designed to use electronic medical records as source of their registry data. Electronic medical records and in general, point of care systems (POCSs) are not fully standard and compatible with international standards. Thus, any point to point communication especially in national registries would be costly. In this regard, SEPAS has created a unique opportunity for establishment of disease registries in Iran.

The prerequisite to this data communication is that the disease registry information systems become compatible with SEPAS data standards and ensure semantic and functional interoperability. Semantic Interoperability refers to the ability of software to transfer content in standard form using standard codes and concepts, while functional interoperability refers to the ability of software to transfer content in a correct and standard structure. Currently, we are working with all pathology centers in the country to create a national data repository for pathology reports that is the basis for PBCRs. All laboratories and vendors that provide laboratory information system were mandated to update their software and include SEPAS standards and ICDO coding in their systems. The pathology reports will be submitted to SEPAS as soon as they are prepared and signed for the patients care in both public and private hospitals. In addition, we have established a database from cancer patients who

were hospitalized in different cancer centers or received cancer specific services. This database will be used in the PBCRs to complete patient information and improve quality indicators, including validity, completeness, and timeliness.

Monitoring and Evaluation

We considered an evaluation system to assess the medical universities in supporting and promote the registry program. We used a life cycle approach to design this evaluation system. The details of our evaluation system are presented in Box 1. All the 50 medical universities were obliged to report status of their registry programs based on the monitoring indicators provided in Box 1. The medical universities will be ranked based on the sum of the scores obtained from the registry programs that are established in their departments, hospitals, or research centers.

Achievements

Since 2004, we managed to establish a large number of registry programs to support clinical research and create a platform for evaluation of the public health programs and quality of care for different diseases and health outcomes in I.R. Iran. We received more than 100 proposals and approved about 52 registries to be funded by the MOHME (Table 1). The registries were established in the national or regional level.

Among the others, establishment of PBCRs were successful and all medical universities established a cancer registry office and assigned a director to develop the PBCR program and implemented it in the region. So far, three provinces have completed all the processes for PBCRs, including Golestan province in the northeastern part of Iran, Fars province in the southern part of Iran, and East Azerbaijan province in the northwestern part of Iran. These provinces prepared their annual reports and estimated incidence and mortality rates for different

cancer types in their region and became role models for other provinces. The data from other regions are coming and we hope that there will be at least 10 PBCRs with standard procedures and accurate estimates for incidence and mortality of cancer in the country. The results from these registries can be used to estimate national statistics for cancer and use it for planning and evaluation of the cancer control programs in Iran. As there is limited data on cancer incidence in the Western Asia and Middle East region, data from this registry can be used to estimate cancer incidence and mortality in the region. In addition, this experience can be used to establish PBCRs in the neighboring countries.

Another important achievement was establishment of registry program for other non-communicable diseases, including cardiovascular diseases, diabetes, and respiratory diseases. Cardiovascular diseases are the most common cause of death in all countries in the world, including Iran. We put particular emphasis on this program and supported the national cardiovascular disease research network to run multicenter registry program for registration of myocardial infarction. The data from MI registry will be available in at least 10 provinces to monitor the quality of care and outcome of patients with MI in different regions of Iran. In Fasa city, the MI registry applied population-based approach and aimed to estimate incidence and prevalence of MI in the region.²⁹

Large universities including Mashhad, Tabriz, and Shiraz universities of medical sciences established a dedicated office to support investigators for establishment of registries in their region. Medical universities organized several workshops in the regional level. Finally, information technology companies have joined the registry programs and several registry software programs were developed to facilitate different aspects of the registries, including registration, quality checks and validation, supervision, analyses and reporting.

Box 1. Evaluation indicators of patient registry programs in I.R Iran

Phase 1: Initiation

1. Submit the proposal of patient registry program
2. Develop guidelines, data collection form, and registry manual
3. Design appropriate database and software
4. Collaboration with researchers and organizations in the national and international level
5. Performing Pilot phase

Phase 2: Implementation

1. Data collection and registration is routinely done
2. Performing Quality Control
3. Preparing Annual Report

Phase 3: Maintenance

1. Data Collection and registration of the data in a routine process.
2. Using data from patient registry in research programs.
3. Using the results from patient registry in clinical practice, policy making.
4. Performing Quality Control
5. Annual Report

Discussion

The MOHME launched a national program and supported medical universities, hospitals, research centers and individual researchers to establish registry systems to improve public health programs, quality of care, and biomedical research. We prioritized the national needs and also considered the interests of the researchers in different disciplines. Establishment of PBCRs was the most important priority and we supported establishment of PBCRs in different provinces and managed to estimate cancer incidence and mortality in three provinces, including Golestan, Fars and East Azerbaijan provinces. In addition, we prioritized registry programs for cardiovascular and other non-communicable diseases,

Table 1. Patient Registry Programs Established and supported by the Ministry of Health of I.R. Iran Since 2014, in Alphabetical Order

| Number | Registry Name | Year Established | Geographical Extent | Scope | Executive |
|--------|--|------------------|---------------------|---------------|--|
| 1 | Alzheimer Disease | 2016 | Regional | Clinical | Iran UMS |
| 2 | Asthma and Allergy | 2016 | National | Clinical | Tehran UMS |
| 3 | Autism | 2015 | National | Clinical | Tehran UMS |
| 4 | Autoimmune Bullous diseases | 2015 | National | Clinical | Tehran UMS |
| 5 | Autoimmune Hepatitis | 2016 | Regional | Clinical | Tabriz UMS |
| 6 | Brucellosis | 2014 | National | Clinical | Hamadan UMS |
| 7 | Burn Registry | 2017 | Regional | Clinical | Iran UMS |
| 8 | Pulmonary Cancers | 2016 | Regional | Clinical | Shahid Beheshti UMS |
| 9 | Cardiovascular diseases (10 provinces) | 2014 | National | Clinical | Iranian Network of Cardiovascular Research |
| 10 | Celiac Disease | 2015 | National | Clinical | Tehran UMS |
| 11 | Chronic Obstructive Pulmonary Disease (COPD) | 2016 | Regional | Clinical | Shahid Beheshti UMS |
| 12 | Chronic Sinusitis with Nasal Polyps | 2016 | Regional | Clinical | Iran UMS |
| 13 | Cochlear Implants | 2015 | Regional | Clinical | Ahvaz UMS |
| 14 | Congenital Anomalies | 2003 | National | Public Health | Tabriz UMS |
| 15 | Cystic fibrosis | 2016 | Regional | Clinical | Tabriz UMS |
| 17 | Diabetes | 2016 | National | Clinical | Tehran UMS |
| 18 | Divorce | 2016 | Regional | | Gonabad UMS |
| 19 | Duchene and Becker Muscular Dystrophy | 2009 | National | Clinical | Pasteur Institute of Iran |
| 20 | Childhood Endocrine Disorders | | National | Clinical | Tehran UMS |
| 21 | Food Allergy | 2016 | National | Clinical | Tehran UMS |
| 22 | Hereditary Retinal Dystrophies and Degenerations | 2016 | Regional | Clinical | Shahid Beheshti UMS |
| 23 | HTLV-1 | 2016 | Regional | Clinical | Mashhad UMS |
| 24 | Hydatid Cyst | 2016 | National | Clinical | Kerman UMS |
| 25 | Rheumatologic Disorders | 2015 | National | Clinical | Tehran UMS |
| 26 | Intensive Care Unit | 2016 | Regional | Clinical | Shiraz UMS |
| 27 | Leishmaniosis | 2013 | Regional | Clinical | Sabzevar UMS |
| 28 | Multiple Sclerosis | 2016 | National | Clinical | Tehran UMS |
| 29 | National Tumor Bank | 2016 | National | Clinical | Tehran UMS |
| 30 | Neonatal Intensive Care Unit (NICU) | 2015 | National | Clinical | Tehran UMS |
| 31 | Nonalcoholic Fatty Liver Disease | 2016 | Regional | Clinical | Shiraz UMS |
| 32 | Morbid Obesity | 2014 | Regional | Clinical | Iran UMS |
| 33 | Olfactory Disorders | 2016 | Regional | Clinical | Iran UMS |
| 34 | Pituitary Tumors | 2014 | Regional | Clinical | Iran UMS |
| 35 | Poisoning | 2016 | Regional | Clinical | Mashhad UMS |
| 36 | Population-based Cancer Registry (10 Provinces) | 2006 | National | Public Health | 10 Medical Universities |
| 37 | Hospital Based Cancer Registry | 2015 | Hospital | Clinical | Tehran UMS |
| 38 | Familial Breast Cancer Registry | 2015 | National | | Tehran UMS |
| 39 | Post-intubation Tracheal Stenosis | 2016 | Regional | Clinical | Shahid Beheshti UMS |
| 40 | Preterm Labor | 2013 | Regional | Clinical | Sabzevar UMS |
| 41 | Pulmonary Arterial Hypertension | 2016 | Regional | Clinical | Shahid Beheshti UMS |
| 42 | Hereditary angioedema ³⁰ | | | | |
| 43 | Orphan Lung Diseases | 2015 | National | Clinical | Tehran UMS |
| 44 | Sarcoidosis | 2016 | National | Clinical | Shahid Beheshti UMS |
| 45 | Schizophrenia | 2016 | Regional | Clinical | Tabriz UMS |
| 46 | Spinal Cord Injury | 2014 | National | Clinical | Tabriz UMS |
| 47 | Stroke | 2016 | Regional | Clinical | Tabriz UMS |
| 48 | Thalassemia | 2016 | Regional | Clinical | Mazandaran UMS |
| 49 | Twins Registry | 2015 | National | Public health | Tehran UMS |
| 50 | Thyroid Cancer | 2016 | National | Clinical | Tehran UMS |
| 51 | Traffic accidents | 2016 | Regional | Public health | Tabriz UMS |
| 52 | Trauma Registry | 2014 | National | Clinical | Tehran UMS |

including diabetes and respiratory diseases.

Although Iranian registries are in their initiation phase and most of them are very young, the progress seems to be promising and we believe that most of them will be sustained and operate in long term and will support both researchers and policy makers. The key to success was to

rely on the institutional capacities and involve research groups that needed the data for public health and clinical research. The main challenge in the future will be providing a sustainable budget. Although we provided 3-year grants for these registries, a maintenance budget is needed to make sure that the registries will live for a

long period of time. We have encouraged the registries to apply for grants from other sources and define a proper business plan to obtain additional funds from local and international grants agencies. Monitoring and evaluation of the registries will provide information on the benefit of these registries for public health and clinical programs, and promotion of biomedical research. In fact, the registry programs involved different stakeholders and created an optimal opportunity for conducting health system research, which was emphasized by the WHO.^{31,32}

One of the important challenges would be ethical issues in the use of data by these registries. We are collaborating with the national research ethics committee to develop a national guideline about data sharing policy and set standards and regulations on how to use public data to establish a registry and how to share the registry data for research and other purposes.³³ Another issue is application of electronic medical records (EMRs) and SEPAS system in the development of disease registry programs. With the advances in the information technology and available infrastructure in the local and national levels and the opportunity of SEPAS database in Iran, it will be more efficient and feasible to establish new registry programs in the future. However, training and guidelines are needed to introduce this opportunity and provide access to SEPAS database for registry programs. It is important to note that there are several drawbacks in using electric medical records. The important caveat is extended and validity of the data, both of which can be improved through collaboration of registry programs and information technology department in the MOHME and medical universities. The example of applying SEPAS middleware to improve quality of pathology reports and enhance PBCRs can be used as a role model and extend application of SEPAS software to other registries.

Conflict of Interest Disclosures

The authors have no conflicts of interest.

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