



Disease registry system in northwest of Iran: The first step forward in research progress with review of literature

Javad Aghazadeh¹ , Habib Pirnejad², Iraj Mohebbi³, Ali Tabrizi*⁴ , Mohammad Heidari⁴

¹ Department of Neurosurgery, School of Medicine, Urmia University of Medical Sciences, Urmia, Iran

² Department of Health Information Technology, School of Allied Medical Sciences, Urmia University of Medical Sciences, Urmia, Iran

³ Department of Occupational Health, Clinical Research Development Unit, Imam Khomeini Hospital, Urmia University of Medical Sciences, Urmia, Iran

⁴ Clinical Research Development Unit, Imam Khomeini Hospital, Urmia University of Medical Sciences, Urmia, Iran

Article info

Article History:

Received: 11 May 2019

Accepted: 23 May 2019

ePublished: 10 Sep. 2019

Keywords:

Disease Registry,

Iran,

History,

Research Program

Abstract

Public health monitoring and evaluation is one of the basic goals in every healthcare system. In this regard, registration system can be used as a powerful tool in disease monitoring, understanding the types of treatments and outcomes, testing effective factors in disease prediction and quality of life, describing care patterns such as care adequacy and care delivery differences, evaluating the effectiveness, and monitoring the safety, damage, and quality of care. In Iran, especially in the northwest of the country, significant steps have been taken in this field which could have important implications for the study design and planning of therapies in the future.

Citation: Aghazadeh J, Pirnejad H, Mohebbi I, Tabrizi A, Heidari M. **Disease registry system in northwest of Iran: The first step forward in research progress with review of literature.** *J Anal Res Clin Med* 2019; 7(3): 70-4. Doi: 10.15171/jarcm.2019.014

Introduction

Monitoring and evaluation of public health require systematic data collection, analysis, interpretation, and dissemination which serves as bases for future plans in chronic diseases management.¹ Registration systems play an important role in managing and analyzing the data related to diseases, complications, mortality, and morbidity. Registration systems are created for scientific and clinical purposes, whose correct design and implementation can provide a realistic view on clinical studies and disease outcomes as well as treatments safety and efficacy.² The first attempts in chronic disease registry in Iran date back to 1955, by establishment of

cancer institute in University of Tehran, Tehran, Iran (now the institute is a part of Tehran University of Medical Sciences).³ In 1956, the first data from cancer registry were published by Etemadi et al.³ In this report, we described registry systems in northwest of Iran, efforts made, and their impact on research programs.

History of registry in the world and Iran

The oldest registry system addressed the cancer.^{3,4} In 1930, cancer registry was developed to prevent and control cancer. Also, the first cancer registry program of other countries initiated in Hamburg, Germany (1927), New York, United States

* Corresponding Author: Ali Tabrizi, Email: ali.tab.ms@gmail.com



(US) (1940), Connecticut, US (1941), and Denmark (1942).^{3,4} Currently, the National Cancer Institute (NCI)'s surveillance, epidemiology, and end results (SEER) program is a coordinated system of cancer registries, strategically located in the US, whose main responsibility is recording accurate data of cancer incidence, mortality, treatment, and survival.¹ SEER was established in 1973 in response to the National Cancer Act of 1971, which mandated the collection, analysis, and dissemination of data regarding patients with cancer for cancer prevention, diagnosis, and treatment in US.¹ Today, registry systems regarding cardiovascular, chronic kidney, metabolic, trauma, and neurological diseases are established in public health care of many countries.⁵ Iran has the most recent cancer registration system in which the data are collected and used in research programs.^{3,4} Also, the burn registry system is a developed program in Iran (with the cooperation of Iran Burn Research Center) which is intended to collect exact and accurate data from all over the country.⁶ The trauma registry system, with 13 trauma centers in Tehran, is another registry system whose preliminary results are published.⁶

Aims of registry

Basically, the registration system follows four major goals: description of the natural course of the disease, determination of the cost of effectiveness or clinical effectiveness, assessment or monitoring the patient safety, and quality measurement.^{7,8} Registration systems may be created to evaluate the natural course of the disease. Natural course possibly varies depending on geographic regions or population and time. In most cases, the natural course of the disease was not properly described.⁷⁻⁹ In addition, the natural course of illness has possibly changed after introducing certain treatments. For example, a registration system showed that patients who had rare lysosomal diseases could survive until their 20s; they now live up to the age of 40.¹⁰

Registration systems can be used to

determine the global cost-effectiveness or clinical effectiveness.¹¹ Several studies have shown the relationship between clinical studies results and the results of the practice.¹¹ In addition, the effectiveness of clinical studies on a particular number of patients is not universal.^{11,12} For example, a large number of clinical studies on cardiac arrest have been performed on people older than 60 years, while in reality, older patients have higher rates of mortality than what the studies report.¹²

Some registration systems can be also useful for the long-term effectiveness of outcomes. For example, growth hormone registry systems should be followed up in target patients from childhood to adolescence.¹³ In addition, registration systems are also used to assess the cost-effectiveness, a tool for describing the comparative value of a product or healthcare service.¹³ The cost analysis shows the benefits of an intervention in terms of its cost. For example, by analyzing the cost of joint replacement surgery, the annual cost of delay in re-surgical joint replacement can be obtained.^{13,14}

Registration systems may be developed to evaluate patient safety.⁹ Here, by safety we imply the patient safety. One of the goals of registration system is to investigate the health and safety risks. In general, the patient safety record system is an active monitoring tool to indicate the harmful events for the patients induced by services or products.⁹⁻¹⁵

Registration systems can assess the quality as well. Institute of Medicine (IOM) defines quality as a degree to which the health services increase the chance of health-related outcomes in accordance with professional knowledge.^{15,16}

These registry systems are based on performance measurements and compare treatment or outcomes in terms of gold standards. While each of the above objectives can create a system for registration, there are also registry systems that pursue more than one goal. For example, the rare disease registration system is a multi-purpose system

that, in addition to following the natural history of patients with rare diseases, seeks to determine the cost-effectiveness or follow-up of injuries in these patients.¹⁵⁻¹⁷

Primary results of registry system in northwest of Iran

Initial steps to establish and complete the required hardware for registry system in northwestern Iran were taken in 2015. In this regard, Urmia University of Medical Sciences, Urmia, Iran, has promoted this goal. To complete the project on registration system, the cooperation with Tehran University of Medical Sciences (a highly experience institute in this field) was very helpful. Currently, Urmia University of Medical Sciences has 8 projects in disease registration system. These projects include: 1. trauma (in cooperation with Tehran University of Medical Sciences) since 2016, 2. spinal cord injury (in cooperation with Tehran University of Medical Sciences) since 2016, 3. population-based cancer registry (covering incidence and prevalence of different cancers in West Azerbaijan Province), in which the data are collected from clinical pathology/cytology center, hospitals, and clinics, center for distributing narcotics for patients with cancer, and the only registry of mortality in the province. So far, our official reports for years 2014 and 2016 were published and reports of 2016 and 2017 are getting ready, 4. hospital-based cancer registry to be started in Imam Khomeini Academic Center of Urmia University of Medical Sciences, 5. celiac disease registry started in 2015 in Imam Khomeini and Motahari Academic Centers of Urmia University of Medical Sciences, 6. chronic kidney disease (CKD) registry (we are the founder of this registry, no other similar registry exists in Iran yet) since 2015, 7. infertility registry (in cooperation with Mashhad University of Medical Sciences, Mashhad, Iran) since 2016, and 8. registry of twins (in cooperation with Tehran University of Medical Sciences) to be started soon.

The system of trauma registration

encompasses 2784 cases, which is based on figure 1.

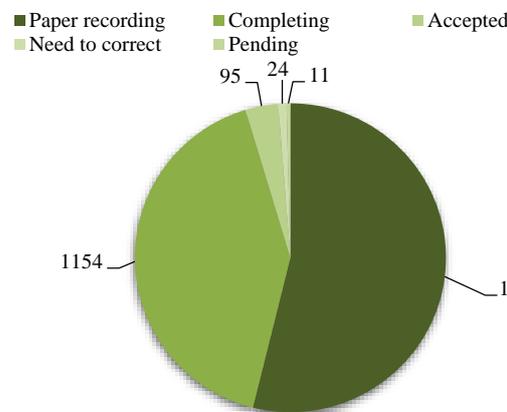


Figure 1. Frequency of data collection in northwestern Iran registry system

According to the existing registries data, the registration system of Urmia Medical Center was the highest compared to other centers of the same level (Figure 2). The number of approved proposals increased 50% based on the data of the registered centers. Ethics Committee has a comprehensive supervision on all the registered centers. Information of these centers has been published in 12 Information Sciences Institute (ISI) papers in the last two years, indicating a significant development for northwest of Iran universities.

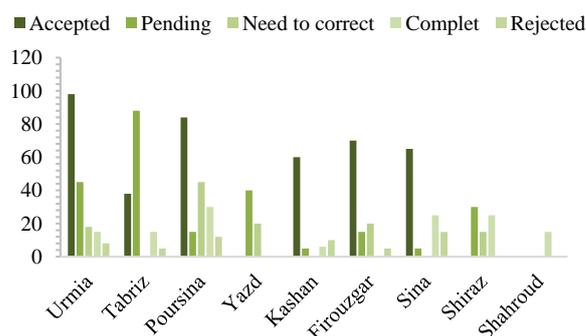


Figure 2. Comparison of data collection in registry system with other equivalent centers of registration in other sites

Discussion

Observational studies and randomized controlled trials (RCTs) with focus on specific therapeutic interventions are the basis of evidence-based medicine,⁵ but the registry

system data can be effective in both fields: patient-specific factors and a broad range of treatment variables.⁵ The RCT studies suffer from various limitations. With the development of societies and expansion of the population, we are faced with a dramatic increase in chronic and traumatic diseases. Regarding the fact that registration systems play a significant role in designing and planning of cohort studies, in relation to RCTs, induced fueled criticism has impeded the establishment and progress of registries.⁵ In comparison with RCTs, registration system could have distinct effects on complementing earlier translational research phases; moreover, it is related with patient care across diverse clinical settings. In addition, financial constraints and research priorities may promote RCTs practice and limit the scope of registration systems.⁵ Registration system, however, covers a wide range of goals and can be extensively used in cancer, infectious disease, trauma, and cardiovascular disorders, where outcomes of research highly affect the public health.²⁻⁵

Our experience about cancer registration is very valuable.^{3,4} Etemadi et al. say that population-based cancer registries and establishment of new registration system in the deprived areas of the country will improve cancer reporting in the country.³ Mohagheghi and Mosavi-Jarrahi reviewed the data collection of cancer registration systems in Iran and expressed that establishment of the regional population-based cancer registry, in cooperation with the Cancer Institute of Tehran metropolis, has brought a better picture of cancer distribution throughout the country.⁴ Furthermore, the burn registry program in Iran especially in Shiraz City provides demographic data, etiological data, and basic criteria for evaluating each burn hospital and comparing their results and outcomes.⁶ It also provides a basis for comparing different treatment plans and evaluating the efficiency of treatments and pre-hospital care.^{4,6} There is also a good experience in the trauma registration system in Iran.¹⁷ Based on the results of registration system in trauma, Zargar et al. showed that

most of the traumatic patients are male patients in second and third decade of their lives.¹⁷ Traffic accident was the main cause for the majority of our patients but victims of assault sustained more severe injuries than other patients. Young men sustained more and severe facial injuries.¹⁷ Patient registry system is generally used for studies in which the registration system is made.¹⁸ Registration systems are widely used in cohort studies. Researches derived from the patient registration system follow patients generally over time. Unlike traditional cohort studies, registry-based studies are generally more flexible and can be changed over time as needed.¹⁸ The registration system can be used as a powerful tool in monitoring the disease, understanding the types of treatments and outcomes, testing effective factors of disease prediction and quality of life, describing care patterns such as care adequacy and care delivery differences, evaluating effectiveness, and monitoring the safety, damage, and quality of care.^{9,18} Registration systems are also employed to study quality improvement through functions such as data feedback.

Conclusion

Generally, the patient registration system is an organized system which applies observational study methods to collect clinical data to assess the specific consequences for a given population, disease, or exposure and follow certain clinical and scientific goals.

Acknowledgments

This study was financially supported by Urmia University of Medical Sciences.

Authors' Contribution

All of the authors contributed equally.

Funding

Funding was done by the office of Vice-Chancellor of Research of Urmia University of Medical Sciences.

Conflict of Interest

Authors have no conflict of interest.

Ethical Approval

This study was confirmed by Ethics Committee

of Urmia University of Medical Sciences.

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