

Comparative study on the National Renal Disease Registry in America, England and Iran

Sima Ajami, Mahdi Askarianzadeh¹, Sakineh Saghaeiannejad-Isfahani², Mojgan Mortazavi³, Asghar Ehteshami²

Department of Health Information Technology and Management, Health Management and Economics Research Center, ¹Department of Statistics and Computer in Health, Health Network Ardestan, Isfahan University of Medical Sciences, Ardestan, ²School of Medical Management and Information Sciences, ³Isfahan Kidney Diseases Research Center, Department of Nephrology, School of Medicine, Isfahan University of Medical Sciences, Isfahan, Iran

ABSTRACT

Context: A disease registry is a database that includes information about people diagnosed with specific types of diseases. The registry collects information that can be used for capturing, managing, and organizing specific information for patients. **Aims:** The aim of this study was to identify and compare the National Renal Disease Registry (NRDR) in selected countries including the United States, United Kingdom, and Iran. **Settings and Design:** Retrieval of data of the NRDR performed through scholars responsible in related agencies, including the Ministry of Health and Medical Education, and Renal Disease charity, and data registries in the United States, United Kingdom, and Iran. **Materials and Methods:** This research was an applied and descriptive, comparative study. The study population consisted of the National Renal Disease Registry of the selected countries including the United States, United Kingdom, and Iran, from which data were collected using forms that were designed according to the study objectives. Sources of data were researchers, scholars responsible in related agencies, including the Ministry of Health and Medical Education, and Renal Disease charity, data registries, articles, books, journals, databases, websites, and related documents. Data were gathered through phone, e-mail, study, observation, and interview. **Statistical Analysis Used:** The researchers collected data for each country based on the study objectives and then put them in comparative tables. Data were analyzed by descriptive, comparative, and theoretical methods. **Results:** There is no NRDR in Iran to report the short- and long-term results of renal disease. Most of the renal transplant teams

report their own results as single-center experiences. America and Britain have pre-eminent national registry of renal disease, compared to other countries. **Conclusions:** The Iranian Society of Nephrology should be actively involved to create a National Renal Registry in Iran. The registry should have representatives from the universities, government, armed forces, and private sectors. Researchers proposed to design the Iran National Renal Registry according to the UK Renal Disease Registry model because of its prominent healthcare system.

Key words: National, registry, renal disease

Address for correspondence: Prof. Sima Ajami, Department of Health Information Technology and Management, Health Management and Economics Research Center, School of Medical Management and Information Sciences, Isfahan University of Medical Sciences, Hezarjerib Avenue, P. O. Box: 81745-346, Isfahan, Iran. E-mail: ajami@mng.mui.ac.ir

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INTRODUCTION

With new challenges existing in health care in the new millennium, people face the growing trend of non-communicable diseases such as renal disease.^[1] The renal disease is one of the causes of death in the world. This disease is very closely related to diabetes, hypertension, and cardiovascular diseases.^[2]

Up to 2011, about 40,000 renal diseases were recognized in which 15,000 have been related to dialysis and 25,000 to kidney transplantation in Iran. Each year, more than 1800 kidney transplants are performed in Iran. But this is not the actual statistical data about people having renal diseases in Iran because many of them are not reported. The global estimate is that 1 out of every 10 people is diagnosed with kidney disease. The current data show that about 500 million people worldwide are suffering from kidney disease; but in Iran, because of the limitations in prevention, prognosis, and treatment equipment, the rate of prevalence of renal disease is more than in the rest of the world.^[2]

Considering the impact on socioeconomic status, and the importance of diagnosis, prevention, and treatment of renal disease in patients without delay, we need to implement the infrastructure for electronic health records (EHR). To prevent, assess, improve the quality of care, develop control programs, and identify the groups at risk of diseases such as kidney disease, we need to have registration systems.^[3]

A disease registry is a database that contains information about people diagnosed with specific types of diseases. The registry collects information that can be used for capturing, managing, and organizing specific information for a population of patients. Disease registries are either clinical-based or population-based.^[4]

The aim of this study was to identify and compare the National Renal Disease Registry (NRDR) of selected countries including the United States, United Kingdom and Iran.

MATERIALS AND METHODS

This study was an applied and descriptive, comparative study. The study population consisted of the NRDR in selected countries including the United States, United Kingdom, and Iran, from which data were collected using forms that were designed according to the study objectives. Sources of data were researchers, scholars responsible in related agencies, including the Ministry of Health and Medical Education, and Renal Disease Charity, data registries, articles, books, journals, databases, websites, and related documents. Data were gathered through phone, e-mail, study, observation, and interview. The researchers collected data for each country based on the study objectives and then put them in comparative tables. Data were analyzed by descriptive, comparative, and theoretical methods.

RESULTS

The present study focused on the NRDR in the selected countries (the United States of America, United Kingdom, and Iran). A comparison of all the NRDR characteristics in the selected countries is shown in Table 1. The results are as follows:

The NRDR history

USA has done the most pioneering work in the field of the NRDR and the data have been recorded since 1988.

The NRDR goals

The goals of the NRDR were formulated both in the USA and the Great Britain. Setting goals is important mainly because the data collection is based on writing goals in the NRDR. As there is no NRDR in Iran, the goals are also uncertain.

Data collection in the NRDR

The data from the USA and UK registries had been collected through three methods as follows: software, the web (online), sometimes paper based. Because of developments in the internet technology, using web-based method was dominant.

Data elements in the NRDR

In the USA and UK, the data elements in the NRDR were almost the same. The data elements in the NRDR are as follows:

- Identifier: Name, National Registration Identity Card (NRIC) No., other ID documents, Address, Contact numbers
- Demographic: Age, Sex, Ethnicity, Level of education, Jobs, Family income, Height, Weight, Tobacco use, Capital treatment
- Medical history: Medical history, Co-morbidities, and Family history
- Diagnosis of end-stage renal disease (ESRD): The primary diagnosis, Date of re-enters (re-write) every data such as renal replacement therapy (RRT)
- Laboratory results: Time and date of test, Blood chemistry, Hematology, Serology
- Treatment plans: Renal replacement report, Hemodialysis, Peritoneal dialysis, Treatment of uremic complications, Kidney transplant
- Consequences: Feet ulcer, Date of death, Cause of death, Quality of life and job, The rehabilitation
- Financial: Funding for dialysis therapy, Financial resources for supporting medication safety (immunosuppressive), Financial resources for the treatment of graft
- Healthcare provider: Dialysis unit [Private, Public, Nongovernment organization (NGO)].

Analysis and distribution of information in the NRDR

In USA and UK, according to various geographic areas, race, ethnicity, and the cost of care, data in the NRDR were analyzed and the prevalence and incidence of diseases were calculated. Also, the data are continuously available for users

Table 1: Comparison of kidney disease registry systems in selected countries

Comparison criteria	Selected countries		
	United States of America	United Kingdom	Iran
Features of Renal Disease Registry			
National Registry name	United State Renals Data System (USRDS)	United Kingdom Renal Registry	There is no national registry
Startup	1988	1992	2008
Extension registry	Nationally	Nationally	Provincial
Goals			
Writing goals registration system	✓	✓	Unknown
Data collection method			
Web-based data collection	✓	✓	×
Data collected through software	✓	✓	Some demographic data
Paper-based data collection	✓	✓	✓
Data elements			
There are registration forms and data elements of the same	✓	✓	✓
Demographic data	✓	✓	✓
Clinical data	✓	✓	✓
Experimental data	✓	✓	✓
Treatment data	✓	✓	✓
Outcome data	✓	✓	Somewhat
Analysis and distribution of information			
The process of analyzing recorded in the system	✓	✓	Somewhat
The process of distributing is regular	✓	✓	Somewhat
Data distributed via web	✓	✓	×
Data distributed via charts	✓	✓	×
Custodians			
Establisher	The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)	The Renal Association	Ministry of Health and Medical Education
Supporter	Members of Centers for Medicare and Medicaid Services (CMS), the United Network for Organ Sharing (UNOS), and the ESRD networks, sharing datasets	The Department of Health, the British Association of Pediatric Nephrologists, and the British Transplant Society as a resource for the development of patient care in renal disease	Ministry of Health and Medical Education

who enter their data through the web. In addition, information reports can annually be distributed online through the registry site, which is available for use by proper individuals and stakeholders. Reports are a complete description of the activities and status of kidney disease registry in the country. In Iran, the findings showed there is no NRDR. There are 20 data elements only [Table 1].

DISCUSSION

It has been pointed out that the disease registry system includes the collection, analysis, and interpretation of data in a consistent and systematic manner for the disease, and timely distribution of information to be processed and sorted. The processed data are important for planning, implementing, and evaluating public health activities and clinical activities.^[4]

As Nobakht *et al.* in their study conducted in 2002 in the Taleghani Hospital of Tehran, emphasized that Renal Disease Registry is an important source for allocating and analyzing clinical outcomes in terms of epidemiological.^[5]

In 2010, Najafi *et al.* in their study concluded thus: “Parallel collection of data at the various centers does not follow the same and unit system. So, the National Kidney Registry is necessary to facilitate and improve patient management.”^[6]

In 2009, Aghighi *et al.* In their study entitled “Changing epidemiology of end-stage renal disease in Iran in recent years,” conducted at the organ donation center and certain disease centers of the Ministry of Health in Tehran, emphasized that the rapid increase in ESRD requires formulating prevention strategies in developing countries. They added that there is a national registry of ESRD, maintained by the Ministry of

Health. Since all RRT patients have been registered for the financial support of the government, dialysis and transplant departments should report new patients and their treatment plans to the Ministry of Health.^[7]

Emami *et al.* in their study entitled “Clinical findings of glomerulonephritis” mentioned kidney disease distributed in various geographic populations. Because of lack of NRDR, there is not enough information in terms of incidence and clinical and laboratory characteristics of various glomerulonephritis patients.^[8]

Geddes *et al.* in their study stated a registry of all biopsies is used to determine renal biopsy, the current regional variations, complications, and risk factors for complications of renal biopsy. Certainly, this information can be used to determine the clinical value of renal biopsy in Scotland. For succeeding in the attempt, the Scottish Renal Registry needs to formulate new strategies for retrieving data. They should use electronic and online method to retrieve data.^[9]

Verger *et al.* in their study entitled “An outline and main results French Peritoneal Dialysis Registry” pointed out that French Peritoneal Dialysis Registry is the central database with the focus on peritoneal dialysis. Its main purpose is to analyze and improve their techniques and facilities. Also, due to the wide participation, it will also provide useful epidemiological information. The French Peritoneal Dialysis Registry is divided into different categories and each category covers a particular aspect of peritoneal dialysis.^[10]

Rao *et al.* in their study in 2002 in Boston, United States of America declared that optimizing the care of patients with chronic kidney disease can be the key to improve clinical and economic outcomes in Chronic Kidney Disease (CKD) and ESRD. The CKD is a major public health problem that has been studied insufficiently. There is little information about the consequences, characteristics, mortality, morbidity, and quality of life in patients with CKD. Indeed, recent efforts by the National Kidney Foundation (NKF) have served to define the classification, evaluation, and approach to management of CKD in practice. The Study of Treatment for Renal Insufficiency: Data and Evaluation (STRIDE) registry is an initiative to study CKD patients in Nephrology practices across the country. It is a prospective observational study whose objective is to profile demographic and clinical variables, practice patterns, comorbid conditions, quality

of life, and outcomes in a nationally based sample of CKD patients. Their study showed and explained the design, methodology, and registration in the registry.^[11]

The Iranian Society of Nephrology should be actively involved in creating a National Renal Registry in Iran. The registry should have representatives from the universities, government, armed forces, and private sectors. Researchers proposed to design the Iran National Renal Registry according to the UK Renal Disease Registry model because of its prominent healthcare system.

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