

Developing a provisional and national renal disease registry for Iran

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Background: Disease registry is a database that includes information about people suffering a special kind of disease. The aim of this study was to first identify and compare the National Renal Disease Registry (NRDR) characteristics in some countries with Iran; and second, develop a provisional and NRDR for Iran. **Materials and Methods:** Retrieval of data of the NRDR was performed by scholars responsible in related agencies, including the Ministry of Health and Medical Education, Renal Disease charity, and data registries in the United States, United Kingdom, Malaysia, and Iran. This research was applied, and the study was descriptive-comparative. The study population consisted of the NRDR in selected countries in which data were collected by forms that were designed according to the study objectives. Sources of data were researchers, articles, books, journals, databases, websites, related documents, and people who are active in this regard, and related agencies, including the Ministry of Health and Medical Education, and patient support charity. 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:** Most of the renal transplant teams report their own results as a single center experiences. America and Britain have a preeminent national registry of renal disease compared to other countries. **Conclusion:** Given that control, prevention, and treatment of chronic renal diseases incur high expenses and the disease is one of leading mortality factors in Iran and across the world and since national registry system for chronic renal diseases can provide better tools and strategies to manage and evaluate patients' characteristics as well as risk factors which eventually leads to making better decisions.

Key words: National, registry, renal disease

How to cite this article: Ajami S, Askarianzadeh M, Mortazavi M. Developing a Provisional and National Renal Disease Registry for Iran. *J Res Med Sci* 2015;20:244-9.

INTRODUCTION

Development and growth in every system such as health care system are basically meaningless without information systems. In such systems, managers and police-makers need comprehensive, sufficient, correct, and up-to-date data for planning. Health care system is capable when it can cooperate with other sectors in the framework of national development regulations in order to prevent diseases and preventable deaths. This system uses health information through events registration, data collection, index calculation, standard comparison, scientific analysis and interpretation, reporting and finally feedback. Information is also used to provide efficient and effective services through policies and strategic planning in management.^[1]

In Iran, like other developing countries some progress is observed regarding establishment and implementation of national information systems such as disease national

registry system. However, some of these systems are not still national and integrated, and their activities are limited to special parts of a province. Renal chronic diseases are among health problems that need such systems nationally, efficiently, and effectively in order to control, prevent and deal with the disease.

Renal chronic disease incurs heavy social-economic expenses as well as so many deaths all over the world. This disease has a close relationship with diabetes, high blood pressure, and cardiovascular problems. Up to 2011, about 40,000 people have been identified with renal chronic disease including 15,000 who have been dialysis patients and 25,000 who have had a transplant. In addition, more than 1800 renal transplants are performed in our country annually. However, these figures do not include the total population of renal patients and majority of them are unknown, because according to universal estimations one out of ten people suffers from renal chronic disease. According to

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Received: 02-11-2014; **Revised:** 24-12-2014; **Accepted:** 09-03-2015

current estimations, about 500 million people suffer from this disease across the world and of course, due to lack of preventive and treatment strategies in Iran the prevalence of this disease is higher compared to global average.^[2]

National registry system includes continuous and systematic collection, analysis and interpretation of data associated with a special disease and on-time distribution of processed data at the national level. This processed information is important for planning, implementation, and assessment of public-health as well as clinical activities.^[3]

Navaneethan *et al.* in a study titled "Development and Validation of an Electronic Health Record-Based Chronic Kidney Disease Registry" stated that renal chronic disease is increasing and research is needed regarding different areas of health in order to direct efforts and use proper interventions. Development of renal disease registry based on electronic health document is possible in a big health system. In addition, this registry can help in the improvement of service quality and act as a supplement to continuous efforts all over the country with the aim to develop monitoring project for renal chronic patients.^[4]

Mesquita *et al.* in a study entitled "Renal biopsy findings in Belgium: A retrospective single center analysis" which was done in Brussels, Belgium stated that biopsy is a decisive diagnosis in renal parenchymal patients. Renal biopsy registry is an important tool that can provide valuable data regarding exact and quick epidemiologic description of clinical correlation in renal chronic disease. It follows that national and global renal biopsy registry is important in following patterns of renal chronic diseases in different populations. This information is not only useful for health organization in budgeting health programs, but also important for clinicians in providing better health care services.^[5]

In a study by Ahmadzadeh *et al.*, which was done in Ahvaz with the title of "Chronic Kidney Disease in Southwestern Iranian Children" it is stated that renal chronic disease has different characteristics based on geographical regions and due to genetic variety as well as environmental factors. Intervention and proper medical treatment may delay the progress of the disease, but there is limited information regarding etiology of renal chronic disease in Iran due to lack of a national registry system.^[6]

End-stage renal disease (ESRD) incidence/prevalence data are not available for large parts of the developing world.^[7] Malekmakan *et al.* pointed that a local registry is important to help in identifying the causes of renal failure and develop management and research initiatives to reduce the burden of kidney disease.^[8]

Mahdavi-Mazde *et al.* in a study entitled "Renal replacement therapy in Iran" which was done in Imam Khomeini hospital in Tehran stated that there is a central registry system in Iran and renal replacement therapy (RRT) centers' data are updated in transplant and specific diseases management centers associated with Ministry of Health every season.^[9]

According to reports and studies done in Iran, there is no national and integrated system for renal chronic disease registry in this country and if there is such a system, it is not considered at national level and is just active as a part of a system. Given heavy social-economic expenses of renal chronic disease, the importance of on-time treatment will be obvious and attention to prevention before treatment, on-time, exact, and comprehensive recording of data for decision-making and also on-time prevention in the framework of national registry systems will be necessary. Given the above-mentioned facts, the researcher aimed to investigate the existing status of national renal registry system in Iran. Since there has been no comprehensive and integrated registry system in Iran, characteristics of these systems were studied in developed countries and then compared together in order to find their similarities and differenced to be able to propose proper strategies for establishment of a national and integrated renal registry system in our country.

The aim of this study was to first identify and compare the National Renal Disease Registry (NRDR) characteristics in some countries with Iran; and second, develop a provisional and NRDR for Iran.

MATERIALS AND METHODS

This applied research was among descriptive-comparative study whose population included renal national registry systems of America, England, Malaysia, and Iran. Data resources included articles, books, journals, databases, related websites, other written documents, data registry centers, researchers and professionals who were active in this field as well as related organizations such as Ministry of Health and Medical Education, and specific diseases support charity. Data collection tools included data raw forms, which were completed based on objectives and through study, observation of documents and websites, interview, telephone call, E-mail to data registry centers, researchers and professionals (Health Information Management, IT Management, Medical Records Education) who were active in this field, reference to and interview with officials of related organizations such as Ministry of Health and Medical Education (physician and expert of noncontagious and specific disease center), and patients' support charity. Given that data were collected through raw data forms which included documented resources, its reliability was

obvious; however, data validity was confirmed by some specialists (health information management, medical records education, professor of nephrology) over the country (10 specialists). Since the study was descriptive-comparative, data and information related to each country were categorized based on objectives, and then comparison and theoretical-descriptive analysis was done using comparative tables.

RESULTS

Renal registry system in America, England and Malaysia showed specific characteristics that were investigated under titles of responsible organizations, general issues, data elements, data collection tools, data analysis, and reporting. The results are subsequently presented.

Table 1 shows responsible organizations and supporters of renal registry system in studied countries.

Table 2 shows the start date and the title of renal registry system.

Table 1: Responsible organizations for renal registry system

Country	Explanations
America ^[2,10]	National Institute of US. Diabetes, Digestive, and Kidney Diseases under support of Medicare and Medicaid Insurance Institutes, Organ Donation Network, and Diabetes and Kidney Diseases Network
Malaysia ^[11]	Malaysian Nephrology Association under support of Dialysis Medical Assistants and Nurses, Clinical Research Center in Kuala Lumpur Hospital
England ^[2,12]	England Kidney Association under support of Health Sector in Ministry of Health, British Children Nephrology Association, Kidney Transplant Association
Singapore ^[13]	This registry is supported by Health Ministry and National Federation of Renal Disease. Administrative committee includes public and academic nephrologists, national renal federation, and private sector
Hong Kong ^[14]	This registry is supported by Government
Iran ^[13]	Office of Transplant and Specific Diseases under support of Ministry of Health and Medical Education

Table 2: General issues about renal registry system

Country	Explanations
America ^[2,10]	USRDS, started in 1988 at national level
Malaysia ^[11]	NRR, started in 1992 at national level
England ^[2,12]	United Kingdom Renal Registry, started in 1992 at national level
Singapore ^[13]	SRR, started in 1993
Hong Kong ^[14]	HKRR, started in 1995
Iran ^[15]	Limited registry that has not been at national level and has started its activities since 2008

USRDS = United state renal data system; NRR = National renal registry; SRR = Singapore renal registry; HKRR = Hong kong renal registry

Data collection process in renal registry systems of studied countries

In all three countries, data collection methods were based on-time and location requirements including paper-based, software, and web-based methods. Naturally, with developments in technology and emergence of internet, methods based on web and software are dominant; however, paper forms are also used as draft along with these newer methods.^[10-12]

Analysis and reporting process in renal registry systems of studied countries

In all three countries, different analyses have been done on collected data given the research objectives. Some examples include analysis of the prevalence and incidence of diseases in different geographical regions, disease analysis regarding race and ethnicity, care expenses analysis, analysis of results, and comparison with countries which have renal registry system. Moreover, in all three countries it is possible to distribute information continuously for those users who register their data through web and online. In addition to online distribution of the information, some reports are provided for beneficiaries through registry websites annually. These reports provide a complete description of registry activities and renal disease status in the country.^[10-12]

Data elements of renal registry system in selected countries

In all countries, similar data elements were used and only in some cases data elements were prepared based on geographical and ethnic requirements. However, data elements can be divided into 9 main sections including identifier, demographic, medical records, diagnosis data, laboratory investigations, treatment data, outcome data, financial data, and eventually care providing data.

Objectives of renal registry system in selected countries

Writing goals is important in registry system because data analysis is done based on these objectives and the aim is to achieve written objectives. Objectives can be stated as follows:

- Renal registry system objectives in America:^[2,10]
 - Identification of ESRD population;
 - Determining prevalence and incidence of ESRD and mortality rate;
 - Identification of relationships between patients' demographic information, treatment methods, and illnesses;
 - Providing national data sets in order to support research by special research centers.
- Renal registry system objectives in England:^[2,12]
 - Collection of health and demographic data in order to provide fair access to health care services;
 - Planning for service development;
 - Facilitating audit comparison through exact defined data set tools;

- Data collection for calculation of indices of health care quality in order to facilitate care effectiveness auditing;
- Providing data at national and local level regarding vase mix discussion.
- Renal registry system objectives in Malaysia:^[11]
 - Determining outcomes and influencing factors on RRT outcomes;
 - Evaluation of RRT program;
 - Motivating and facilitating research regarding RRT and ESRD;
 - Keeping national kidney transplant waiting list.
- Renal Registry in Singapore:^[13]
 - It has been established in order to collect and analyze data about incidence, prevalence, illnesses and mortality due to the final step of renal disease.
 - The registry experienced 2-year latency.
- Renal Registry in Hong Kong:^[14]
 - It is an electronic system that acts as a database for patients who receive different renal replacement treatments.
 - Contents of database include demographic data, dialysis and transplant data, complications, research, and report. It can be helpful for management of specific diseases, renal center management, and finally development management.
 - Computer terminals in different renal wards are connected through a central server that is in turn connected to organ provider system and tissue laboratory. In addition, users can register incidents in Hong Kong Renal Registry (HKRR) through clinical management stations across the wards and outpatients clinic.
 - Users access the system through all hospitals and clinics across the country, and patients' data enter the system directly. In addition, this registry acts as an online clinical information system and helps in completion of patients' electronic records as well as special data about renal replacement treatments.
 - Users can restore data on demography, diagnosis, complications during treatment, and chronicles of clinical events including a variety of renal replacement and resulting complications. A summary of clinical events can be received and printed for daily management.
 - In addition, summary of events can facilitate data transmission among renal centers. HKRR is an effective clinical tool for both patients and managers of renal centers. Data saved from different centers are used in policy-making and allocation of resources.

Proposed strategies regarding National Renal Registry System in Iran

- Proposed objectives for National Renal Registry System in Iran:
 - Identification of ESRD population;
 - Determining prevalence and incidence of ESRD and renal disease mortality;
 - Identification of relationships between demographic information, treatment methods, and illnesses;
 - Development of national minimum data sets in order to support research in specific research centers;
 - Collection and analysis of standard data associated with incidence, clinical management, and outcomes of renal diseases;
 - Providing information for auditing and benchmarking, planning, clinical governance, and doing research.
- Proposed method for data collection in National Renal Registry System in Iran:
 - Via web:
 - Given technology development and emergence of internet in many work areas such as health care, this method is the best and fastest strategy for data collection and transmission.
 - In this method, data are recorded directly in national registry system after patient reception and through hospital information management system at the time of patient's hospitalization.
- Proposed responsible organizations for National Renal Registry System in Iran:

It is proposed that Ministry of Health and Medical Education should establish national registry system in which there is a committee including nephrologists, epidemiologists, pathologists, urologists, surgeons, and health information managers for policy-making and planning which aim to design and develop Model Disability Survey (MDS) as well as national renal registry system. These plans will be communicated to the office of noncontagious disease to be implemented [Figure 1].

Proposing a method for data analysis, interpretation, and distribution in National Renal Registry System in Iran

- In order to achieve the objectives of registry system, systematic analysis should be performed based on existing needs;
- Analysis can be done on the number of patients, patients' gender and age distribution, causes and risks of diseases factors;
- Other analysis factors based on patients' existing needs can be related to informing patients about finding a proper kidney;

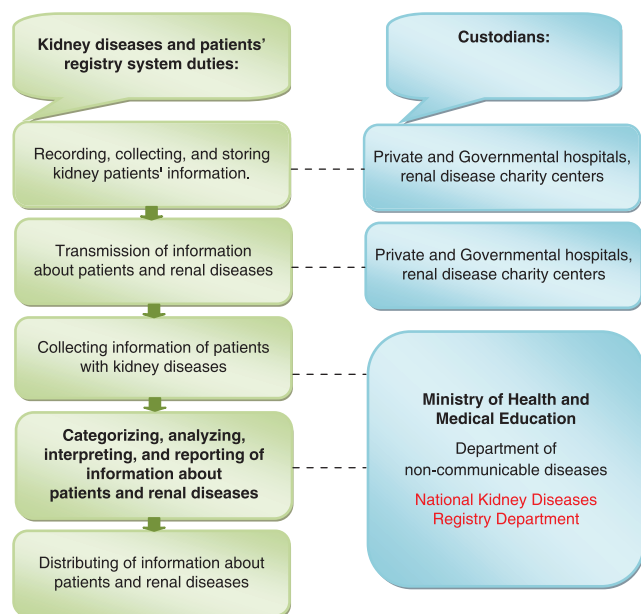


Figure 1: Proposed responsible authorities for different parts of National Renal Registry System in Iran

- After analysis, data are submitted to users through registry website;
- It is possible to prepare reports in specific time intervals and in the framework of tables, graphs, and text;
- The level of access for users and beneficiaries to registry will be determined as much as possible;
- Backup will be prepared periodically in order to protect information;
- In order to prevent probable events (information security) and follow confidentiality of patients' information, different access methods such as user ID and password are used for authorized people. This ID and password will be renewed periodically and given to the associated user.

DISCUSSION

As it could be observed in similar studies done in Iran, America and England were mainly considered as selected countries. Therefore, these countries are pioneers in establishment and implementation of "National Information Registry Systems" in different areas and can provide proper patterns for establishment and development of national registry systems in Iran. Basic characteristics of these information systems include: System responsible organization, general issues, objectives, data collection methods, data storage, data restoring, analysis and interpretation of findings and eventually reporting and distribution of data among organizations and associated people.

Most comparative studies that have been done under the title of national information registry system focus on different areas; however, majority of them obviously state

that there is not such a system in Iran or it's not active at national level. As a result, studies should be done in this regard, and proper strategies should be provided in order to promote national information registry systems in our country.^[2-7]

Yahya *et al.* in a study titled "Analysis of 490 kidney biopsies: Data from the United Arab Emirates Renal Diseases Registry" stated that there is a limited set of data on renal disease in United Arab Emirates. A renal registry was established to deal with this issue, and its results are reported in the study.^[15] In fact, this study is an experience that encourages Iranian planners and designers to develop a proper MDS with sufficient care.

Gesualdo *et al.* in a study titled "The Italian Experience of the National Registry of Renal Biopsies, Italian Immunopathology Group, Italian Society of Nephrology" stated that there are many registries for collecting renal chronic disease data, but there are a few registries that collect specific data on renal biopsy. The Italian Renal Registry Biopsy is an example of this registry in Italy.^[17] In fact, the research suggests that Iranian planners and designers should consider biopsy information in MDS.

Couchoud *et al.* in a study entitled "The Renal Epidemiology and Information Network: A new registry for end-stage renal disease in France" which was done in France said that this registry started its work in 2002 and has provided tools to support public-health decision-making, assessment and research regarding alternative renal treatments for ESRD patients. This registry is supported by a network of nephrologists, epidemiologists, patients and public-health institutes at local and national level. This registry continuously records data about all dialysis and transplant patients;^[18] therefore, it has been successful in providing treatment, prevention, and control objectives.

It should be mentioned that all registries were national, and this was a common feature with similar foreign studies. In addition, epidemiologic research and data standardization were used as efficient and effective tools.

CONCLUSION

Given that renal chronic disease incurs high expenses and is considered as a mortality factor in Iran and given that national renal registry system is a proper method and tool for better management, assessment of patients' characteristics and their risk factors, and finally helping to make decisions for control and prevention of this disease, it seems necessary to establish and develop an integrated and efficient national renal registry system. Obviously, investigation and evaluation of experiences in

other countries that have implemented this system at the national level can help in designing and developing it in Iran. Implementation of such a system will be difficult and expensive at first but since it reduces the burden of renal chronic disease and its outcomes such as mortality, it will be highly cost effective in the future.

RECOMMENDATIONS

- All health care centers and renal disease clinics that send their information to this registry system should have a unique code for easy identification. This code can be a combination of a series of management and geographical information;
- All renal patients write their consent at the back of reception and discharge papers and fill out written consent to record their information in the national registry system.

AUTHOR'S CONTRIBUTION

SA contributed for conducting research project, preparing and editing manuscript, approval of the final version of the manuscript, and agreed for all aspects of the work. MA contributed in the conception and design of the work, drafting and revising the draft, approval of the final version of the manuscript, and agreed for all aspects of the work. MM contributed in the conception and design of the work, drafting and revising the draft, approval of the final version of the manuscript, and agreed for all aspects of the work.

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Source of Support: This article resulted from part of research project No. 393202 funded by the vice chancellor for research of the School of Medical Management and Information Sciences, Isfahan University of Medical Sciences, Iran, **Conflict of Interest:** None declared.