

A Proposal for Data Registry system for Urologic Cancers in Iran

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Purpose: Data registries are organized systems that facilitate the collection, storage, and analysis of data related to a specific disease in a defined population. Here we introduce a data registry system which was designed to cover the four most common urologic cancers (prostate, bladder, renal, and testis).

Materials and methods: All contributing centers can enter data into the system after logging in with their unique usernames and passwords. In this system, the information of each individual patient will be entered in several structured forms covering various steps of management of the patients.

Results: Our proposed registry is an interactive, web-based database designed to collect complete data of patients with common urological cancers. We devised a council that functions as the central committee that will initiate, supervise, and monitor all steps of the projects including data collection, data audit, as well as data analysis and publication. To facilitate manuscript publication, the system will provide assistance and support throughout all the steps of statistical analysis and manuscript preparation.

Conclusion: This proposed registry can have a national target and is designed to provide evidence-based information that could support strategic planning and national multi-centric studies.

Keywords: disease-specific outcomes; epidemiology; population-based; prospective registries; urologic malignancies

INTRODUCTION

In recent years, cancer has become one of the most common causes of mortality in almost all countries across the globe. Cancer is the first and second leading cause of death in developed and developing countries, respectively⁽¹⁾. Despite the recent advancements in cancer treatment, cancer-related complications contribute to the death of many people annually⁽²⁾.

Data registry has an important role in cancer surveillance. It provides an overview of where we stand in terms of cancer prevalence and incidence⁽³⁾. Subsequently, this data can be used to plan and evaluate cancer control strategies and interventions⁽⁴⁾. Nevertheless, single center cohort studies are non-optimal because of strict inclusion and exclusion criteria, highly selective patient groups, as well as feasibility and cost issues⁽⁵⁾. To overcome this limitation, during the past two decades, cancer registry systems have been introduced. These organized systems facilitate collection, storage, and analysis of data related to a specific disease in a defined population⁽⁶⁾.

In recent years, the prevalence of cancer has been increasing in Iran⁽³⁾. In fact, cancer is the second most common chronic non-communicable disease in Iran, and the most prevalent cause of death after heart diseases, accidents and other natural phenomena⁽⁷⁾. Advances in diagnostic methods, rapid industrialization and modernization, and significant life style and environmental changes are thought to account for this rise in cancer

prevalence⁽⁸⁾.

Prostate, renal, bladder, and testis cancer are the most common urologic malignancies. Thus far, many modalities have been introduced to prevent, treat and improve the long-term outcome of these cancers. Although much progression has been made to decrease disease progression and improve cancer-specific survival, there is still a need for further research and studies⁽⁹⁻¹¹⁾. It is worthy to note that prostate and bladder cancer are among the five most common non-cutaneous cancers in Iranian males⁽¹²⁾.

After realizing the importance of the presence of a national cancer registry, a data registry system was designed by the urology department of Shahid Labbafinejad Hospital to cover the four most common urologic cancers (prostate, bladder, renal and testis). The objective of this data registry is to collect data related to urologic cancers at a national level and to provide the required evidence for strategic planning. The goals can be mentioned in more detail as the following: creating a national network of clinical centers and urologists, providing strong infrastructure and support for urology research, creating a national platform that enables prospective and precisely-designed studies to be performed at a large scale, and collection and dissemination of national data related to urologic cancers and urology practice in Iran.

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MATERIALS AND METHODS

All contributing centers can enter data into the system after logging in with their unique usernames and passwords. In this data registry system, the information of each individual patient will be entered in several structured forms covering various steps of the management of patients. To design data entry forms containing a comprehensive set of important characteristics and variables impacting on diagnosis, treatment algorithms, and follow up of each cancer, authors searched in PUBMED and studied several published articles focused on different aspects of each cancer. The content validity of the questionnaire for data entry has been verified by three urologists after the summarization of the retrieved articles. As an example of data collection forms, prostate cancer forms and its included variables are briefly described here. Prostate cancer data is collected in ten forms including general data, preoperative data, TRUS biopsy, radical prostatectomy operative data, pathology, post-operative data, follow up, radiotherapy, hormone therapy, and summary. Each form constitutes of several related variables and provides comprehensive data regarding certain aspects of the disease (supplementary table 1).

These data have already been recorded electronically at the time of admission with patients' permission and the data accuracy is confirmed by the relevant physicians. At the same time, patients are informed that their information will be entered into the data registry system. We intend to recheck the data accuracy at random intervals through re-interviewing random patients and visiting the medical centers which recorded the information. All of these data will be available on the website for the defined users. Furthermore, the program provides reports from entered data in excel format which facilitates statistical evaluation of the data.

RESULTS

Urological Cancers Data Registry (UCDR): The UCDR is an interactive, web-based data registry system designed to collect complete data of patients with common urological cancers. UCDR is easily accessible on the web and can be used by several centers around the country. Hence, multicentric prospective data on each cancer patient can be recorded from the first visit until the last follow up. Moreover, the general structure of the data registry system can be used to design detailed registry for any other disease in the field of urology.

UCDR Council: IUCD council is the central committee that will initiate, supervise, and monitor all steps of the projects including data collection, data audit, as well as data analysis and publication. All content of the website is subject to copyright owned by UCDR.

IUCD council will check the validity of submitted data both online and on-site. UCDR will check the validity of data on-site by randomly assigning supervisors to visit the contributing centers.

Publication: To facilitate manuscript publication, UCDR will provide assistance and support throughout all the steps of statistical analysis and manuscript preparation. UCDR will assign an epidemiologist/biostatistician and a medical editor to actively assist in preparing the manuscripts.

After data collection, subjects of interest for analysis will be suggested by the contributors and UCDR council. The council will consider the suggestions and will

finally select the specific subject for analysis. The contributor who has suggested the chosen subject and/or the council will be responsible for performing statistical analysis and preparing the final manuscript.

DISCUSSION

A healthcare data registry system as a tool for collection and storage of data related to certain diseases and patient management constitutes of uniform structured forms containing comprehensive data elements. The data registry system facilitates performing precise research projects in various aspects of the included diseases and their management. Also, healthcare data registry systems help diplomacy makers to design effective community-oriented programs based on the real situation of the country. The Clinical Research Office of the Endourological Society (CROES) and International Registry in Organ Donation and Transplantation (IRODAT) are two international data registries in the field of endourology and organ donation providing data registry systems and supporting research projects.

A global network is provided by the Clinical Research Office of the Endourological Society (CROES) to promote and support high quality international patient-centered research in a transparent way and to make the implementation of research projects possible. It provides a web-based data collecting and management system and prepares the infrastructure to manage such multicenter studies, including evaluation of the quality of the projects, data collection, statistical analysis and preparation of manuscripts. Through the website: www.croesoffice.org. The users all over the world can collect data with a single username and password for all CROES studies. Many new projects can be defined after being approved by the involved steering committee. To ensure a reliable dataset, all data are controlled daily by CROES data managers and data collection progress is continuously monitored. Global percutaneous nephrolithotomy (PCNL) study, global ureterorenoscopy (URS) study, global greenlight laser study, global renal mass study, and global narrow band imaging (NBI) study are five projects that CROES is conducting⁽¹³⁾.

International Registry in Organ Donation and Transplantation (IRODaT) is the first registry which contains statistics on deceased/living donors and transplants. Eighty six countries with organ donation or transplantation activity have submitted data to IRODaT since 1998. The data from each participant country is inserted into the web form data registry system (<https://www.irodat.org>) and could be verified by contacting the official reporter when needed. The IRODaT team could provide specialized reports in case of specific investigations and studies⁽¹⁴⁾.

Taking examples from similar national and international health registry systems, we designed a data registry system in the field of four common urology cancers to facilitate research, and community-oriented policy making for effective management of the cancers.

CONCLUSIONS

Data registry has an important role in cancer research, and can aid in the development and evaluation of cancer control strategies. By developing cancer registry systems, we can collect and store data of specific malignancies and use it for future planning. Also, these systems allow us to perform data analysis and gain information

about the epidemiology of cancers, as well as to generate research ideas with the aim of improving cancer management and survival. IUCD, as a national cancer registry system, is designed to provide evidence-based information that could support strategic planning and national multi-centric studies.

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CONFLICT OF INTEREST

All authors declare that they have no conflict of interests

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