Brief Communication

Development of a Web-based Glaucoma Registry at King Khaled Eye Specialist Hospital, Saudi Arabia: A Cost-Effective Methodology

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ABSTRACT

In this brief communication, we present the steps used to establish a web-based congenital glaucoma registry at our institution. The contents of a case report form (CRF) were developed by a group of glaucoma subspecialists. Information Technology (IT) specialists used Lime Survey softwareTM to create an electronic CRF. A MY Structured Query Language (MySQL) server was used as a database with a virtual machine operating system. Two ophthalmologists and 2 IT specialists worked for 7 hours, and a biostatistician and a data registrar worked for 24 hours each to establish the electronic CRF. Using the CRF which was transferred to the Lime survey tool, and the MYSQL server application, data could be directly stored in spreadsheet programs that included Microsoft Excel, SPSS, and R-Language and queried in real-time. In a pilot test, clinical data from 80 patients with congenital glaucoma were entered into the registry and successful descriptive analysis and data entry validation was performed. A web-based disease registry was established in a short period of time in a cost-efficient manner using available resources and a team-based approach.

Key words: Congenital Glaucoma, Health Register, Web-Based Registry

INTRODUCTION

Disease registries are important tools for tracking disease trends or treatment outcomes.¹⁻⁴ The health/disease registry could be hospital/clinic-based or population based. The former is used for a specific disease irrespective of the location of the case. Alternately, a population based registry is used to compile information on specified diseases by region, community, and state in which they are diagnosed.⁴ They exist in different formats; paper based registries, the most common types of registries in the past were complemented over time by computerized records. In recent years, web-based registries have become popular because they are user friendly and can be managed from different locations. Additionally, the web-based approach overcomes data management issues and allows for periodic generation of information for monitoring and policy making. Health managers at hospitals, national, and international levels use web-based registries to compile information on different health issues.⁵⁻⁷

Since 1983, paper and computer-based retinoblastoma and tumor registries had been in place at the King Khaled Eye Specialist Hospital (KKESH) Riyadh, Saudi Arabia.⁵⁶⁹ On the basis of the computer-based congenital glaucoma registry, baseline features of primary and secondary congenital glaucoma were described.⁴ Saudi Arabia has one of the highest incidences of primary congenital glaucoma worldwide.¹⁰ However, there is a relative paucity of information on the outcomes of managed children. A simple, yet effective web-based registry was created to prospectively collect data on congenital glaucoma. To the best of our knowledge, web-based registries have not been used to track outcomes or disease trends in congenital glaucoma (CG). We also discuss the validity and cost effectiveness of this registry.

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METHODS

This study was undertaken between January 2012 and March 2013. The approval of research department of (KKESH) was obtained information from paper/computer registry. A registry committee comprising of ophthalmologists, epidemiologist, statistician, information and a technology specialists, and a registry manager was formed.

Two glaucoma specialists prepared a case report form (CRF) that included a questionnaire on congenital glaucoma [Table 1]. They also defined mandatory fields/questions. Information technology specialists provided the Lime Survey form (Lime Survey 2.05, Germany) that is available without cost. All the CRF questions were incorporated as an electronic form in the Lime Survey software. To minimize manual entry by the end user, drop down boxes and check boxes were used for data entry. The biostatistician checked the validity of the case report form to ensure that the questionnaire could gather sufficient information from end users as per the registry manual that was prepared for web-based data entry. A person with basic knowledge of database and programming should be able to use ‘MySQL’ software and create an electronic CRF using ‘Lyme Survey’. The eCRF was then linked to ‘MySQL’ software through a virtual machine operating system in the IT department at KKESH. This system in KKESH is subscription based and is used by numerous departments in the hospital. Hence, use of this system for CGR was a small fraction of the total cost of this service.

To make the registry web based, a Uniform Resource Locator (URL) was created for the CGR. The website could only be accessed with a unique login identification and password. The data manager provided access for data entry via the URL. The web-based CGR was tested by entering the data from different locations. The CGR data was tested and could be exported to common analytical software such as Statistical Package for Social Studies (SPSS, IBM Corp., New York, NY, USA) and R-language.

The individuals involved in establishing the CGR were interviewed to determine the approximate time they spent in developing the online registry. From their responses, we calculated the Full Time Equivalent (FTE). A cost analysis based on FTE spent in establishing a web-based CG registry was performed.

The time required for completing one CGR form was calculated. The time to analyze and interpret the CGR by a data manager was also calculated.

RESULTS

The algorithm to establish the CGR is illustrated in Figure 1. An example of populated drop boxes in the electronic CRF is presented in Figure 2.

The data of 80 patients from an existing paper/computer based CGR at KKESH (2000 to 2003) was entered in the electronic CRF as a pilot project. Descriptive analyses of the 80 cases were performed and plotted using an automatic outcomes function available in the Lime survey software. This exercise enabled a validity check of the computer-based registry.

The time for a clinician or data entry personnel to complete the CRF during clinical assessment was less than 4 minutes.

The web-based registry was easily accessible from different locations following signature. In addition, automated descriptive analysis in a graph format could be generated [Figure 3].

The cost analysis based on the full time equivalent (FTE) spent in establishing web-based CG registry is presented in Table 1.

Table 1: Cost analysis by full time equivalent for establishing a web-based congenital glaucoma registry

| Manpower                      | Number of persons | Human resource/equipment/software | Average man hours used on project |
|-------------------------------|-------------------|----------------------------------|---------------------------------|
| Ophthalmologist               | 2                 | KKESH employees                  | 7                               |
| Information technology team   | 2                 | (1): Virtual machine             | 2                               |
|                               |                   | operating system multi           |                                 |
|                               |                   | user (licensed)                  |                                 |
|                               |                   | (2): http://dev.mysql.com/downloads/mysql |                            |
|                               |                   | (3): http://www.limesurvey.org    |                                 |
|                               |                   | (4): Internet PC/Office space     | 24                              |
| Registry manager/web designer | 1                 | Modification and correction      | 1                               |
| bio-statistician              |                   | Validity testing                 |                                 |

Figure 1: Flow chart of web-based glaucoma registry
**DISCUSSION**

Web-based registries have been previously established in other fields of medicine. Most involve conversion of existing manual and computer-based registries to web-based registries. Experience in other fields of medicine indicated that these registries are sustainable because they are user friendly, easily accessible from any part of the world, provide epidemiological data with minimum errors, and have important applications.

In this study, we outline the process of creating a web-based CGR using “off the shelf” software, and based on our experience it was relatively easy to establish. Some of the key components in making the endeavor successful was to have a knowledgeable ophthalmic and IT team combined with an efficient data entry manager and biostatistician. A cost analysis of the registry included factors such as human resources, equipment, and supplies and it was determined that a product was created at a fraction of the cost of commercially available or customized databases. Some of the cost savings achieved during this project were related to the existing infrastructure in the hospital’s information technology department and the free downloadable software. An accurate estimate of actual cost of commercially available or customize databases was not available despite attempts to procure information on specific costs. However, rough estimates from personal communication with local institutions in Saudi Arabia that maintain registries suggested that the costs of customizing and maintaining registries/databases are much higher.

From the clinician’s perspective, the feedback received was that the data entry was intuitive, quick, and easy, and that allied health personnel could be trained to enter the data. Also of importance was the data could be entered at any workstation connected to the Internet or intranet. We believe that this process which includes additional data entry other than what is entered in the medical record will not decrease the efficiency of clinical practice. The software feature of generating automated descriptive analysis plotted on graphs will help track data in real time enabling the data manager to prepare policy briefs in an efficient manner. Due to the relatively simple IT infrastructure required, we suggest that establishment of similar registries would be feasible in most developing countries. The cost of FTE in each country would differ. Hence, providing cost in terms of “dollars” would not be practical. Individuals from each country that plan to use such a registry would need to calculate costs per FTE.

Since the registry is web-based, it is feasible for such a registry to be used to collect data from multiple centers nationally or internationally and could be created for any ophthalmic condition. The web-based registry has already been expanded to other diseases and pathology such as retinoblastoma, ocular tumors, retinal dystrophies, and keratoconus at our institute. These registries will soon cover the Kingdom and then the gulf countries. Since the IT infrastructure is simple it can be located at only one institution, and the costs associated with creating and maintaining the registry will be further reduced. To the best of our knowledge, such a web-based registry has been created for diabetic patients with data on 10,000 cases.

It is possible that one of the weaknesses of establishing such a registry might be accommodating large data sets. In addition, a potential weakness is the discontinuation of free downloadable software or the absence of technical support for this product in the future may cause difficulties in continuing additional data entry using the same format. However, since the data stored on a MySQL server internally, data that was collected would not be lost. Congenital glaucoma registry information was collected from both glaucoma and pediatric ophthalmology units at KKESH. The pilot was based on transferring retrospective data from a paper-based registry to a web-based registry. The actual data collection henceforth would be prospective. If many institutions are involved in the registry, the time required to register a case...
could be longer than that described in the current study. Cloud testing by external institutions could further strengthen the web-based CGR. Using cloud computing, the development for a larger storage capacity should also be explored.

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