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SPECIAL ARTICLE

The role of information systems in cancer prevention

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ABSTRACT

In recent decades, there has been a dramatic increase in the incidence of colorectal cancer in Iran, especially in patients less than 50 years old. A national colorectal cancer screening program is the best solution for identifying patients in high risk populations. The Research Center of Gastroenterology and Liver Disease of Shahid Beheshti University, M.C., in collaboration, with the Ministry of Health for the Islamic Republic of Iran set up in national screening program. The Research Center of Gastroenterology and Liver Disease designed the information network and semi-intelligent software for required to manage this program in Tehran (the capital of Iran), other provinces and centers providing colorectal cancer screening services.

Keywords: Information system, Colorectal cancer, Prevention
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INTRODUCTION

Colorectal cancer (CRC) is one of the most prevalent cancers and leading cause of cancer mortality worldwide (1). In the United States alone, treatment costs for colorectal cancer were $8.4 billion in 2004 (2). Reports from the annual Iranian National Cancer Registration Report, confirm that colorectal cancer is the third common cancer in women and 5th most common cancer in Iranian men (3). Furthermore the incidence of colorectal cancer has increased during the last 25 years (4). Numerous studies have confirmed that colorectal cancer incidence and mortality are reduced with regular screening (2). Population-based colorectal cancer screening plan is an effective and cost efficient is accurately and efficiently implemented. This implementation is supported by information networks and information systems that supports patients risk assessment, mentoring and assessment (5).

An Information System (IS) is any *combination* of hardware, software, infrastructure and trained personnel organized to facilitate planning, control, co - ordination, and decision making.

IS, as a tool, is advancing into many healthcare programs. IS can be used to support the delivery of cancer prevention services. In addition, IS can provide database facilities; an essential requirement for a national colorectal cancer screening program is a population requiring the base-line registration invitation to attend screening, recall and tracking of high-risk patients (6). IS can identify patients due for screening and calculate their baseline risk of developing colorectal cancer and suggested screening program on the basis of information provided by patients, primary care physicians and practice groups (7). In a national screening plan, high quality, reliable and organized IS can support analysis and decision making.

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INFORMATION SYSTEM AND CANCER PREVENTION

IS uses information technology to capture, transmit, store, retrieve, manipulate, or display information, thereby supporting one or more other work systems (8).

Information technology is rapidly advancing and making its way into many primary care settings. The technology may provide the means to increase the delivery of cancer preventive services (9).

Like many cancers, CRC can take many years to develop. Early detection and treatment of pre-cancerous lesions (colorectal polyps) at colonoscopy is possible and this can prevent CRC from developing. Furthermore, detection of early, localized, CRC also provides an opportunity for curative treatment. Screening can therefore be recommended for individuals who are at increased risk of developing CRC.

GLOBAL VIEWS OF CRC SOFTWARES

Two Models Related to Medical Informatics for Colorectal Cancer Screening

Screening organization should be chosen according to its ability to transfer theoretical efficacy into clinical effectiveness. An evidence-based organizational model of colorectal cancer screening (CRCS) can guide feasibility and encourage high compliance by health care professionals and citizens. In this section were described two types of models, the U.S. and Canadian CRC screening IS.

The first is the CRC screening model currently used for cost-effectiveness analysis in US. The main outputs of model are average years of life lived and accrued costs per person. It can be converted to an aggregate annual model by combining the estimates for every age group in each year and projecting to the national population. Year-2000 U.S. Census data can be combined with age-specific model outputs to make predictions for the U.S. population (aggregate annual model), as opposed to a hypothetical cohort of a given size starting at age 50 years. The model is a Markov model. For the purposes of the pre-workshop modeling exercise, it followed people from 50 to 85 years of age (or until death if younger than 85). The model can be extended to incorporate ages up to age 100. It is also possible to treat each sex separately (though most of our work has been with average values for the entire population). Finally it is possible for the model to evaluate the costs and effectiveness of screening in populations with different levels of risk for polyps and cancer. This model has capability for working on making predictions at the level of the entire population. (10).

The second model is the Canadian jurisdiction-wide CRC screening program - described as a unique initiative for organized population-based cancer screening in Canada. This health IS supports the progress' screening model and includes rule-based decision support to monitor screening frequency. An information system sends reminders to individuals about screening, assists in result analyzing and integration. In designing the cancer screening IS, existing technologies were leveraged to provide the ability to manage patient demographics, provider information, and clinical information, as well as to facilitate integration of rule based notification and reminder and recall components. In addition, the system must support electronic links from laboratories, electronic medical records, and hospital information systems. Key application components, such as the system administration (including security and auditing), the enterprise Master Patient Index (MPI), Messaging System (MS), and the Vocabulary Services (VS), were adopted from available COTS (commercial off-the-shelf), MOTS (modifiable off-the-shelf) and GOTS (governmental off-the-shelf) tools (7).

HISTORY OF THE IRANIAN NATIONAL CRC SCREENING INFORMATION SYSTEM SOFTWARE

The IS semi-intelligent software (figure 1) was designed in three sections (genetics, pathology and clinical information). It was designed to in-corporate standard of information and international clinical and genetic algorithms. Once the overall design had been agreed clinicians (gastroenterologists, pathologists and genetics experts) evaluated the information structure. A final version of the software was then surveyed by clinicians at the Research Center of Gastroenterology and Liver Disease, Shahid Beheshti University, M.C., Tehran, Iran and then approved by the Ministry of Health for Islamic Republic of Iran in 2008.

This software is designed for index CRC cases and assessing asymptomatic individuals on the basis of their family history. Since the users are not professional in computer science, this software has a simple Farsi interface. The CRCreg (our software) is responsible for planning, executing and evaluating population-based cancer screening programs.

A pilot of the software has been performed at the Taleghani Hospital (a teaching hospital and a hub for the national screening plan). This software has also been used in provinces supporting CRC screening. In addition we have performed periodic reviews of software performance and assessed results, especially relating to CRC genetics and surveyed national experts to assess the ease of use and performance of software.

Designing information networks is based on an assessment of information need for the management of predicted activity of covered provinces and other centers related to colorectal cancer. RCGLD acts as a the chief correspondent for the national plan and supports monitoring originations and provides the provinces with a report of activity and also sends this information back to the network centre via the same network.

570 patients and their relatives are entered into the software. Distribution of population by sex and frequency of data elements of national colorectal cancer software were shown in table 1 and figure 2, respectively.

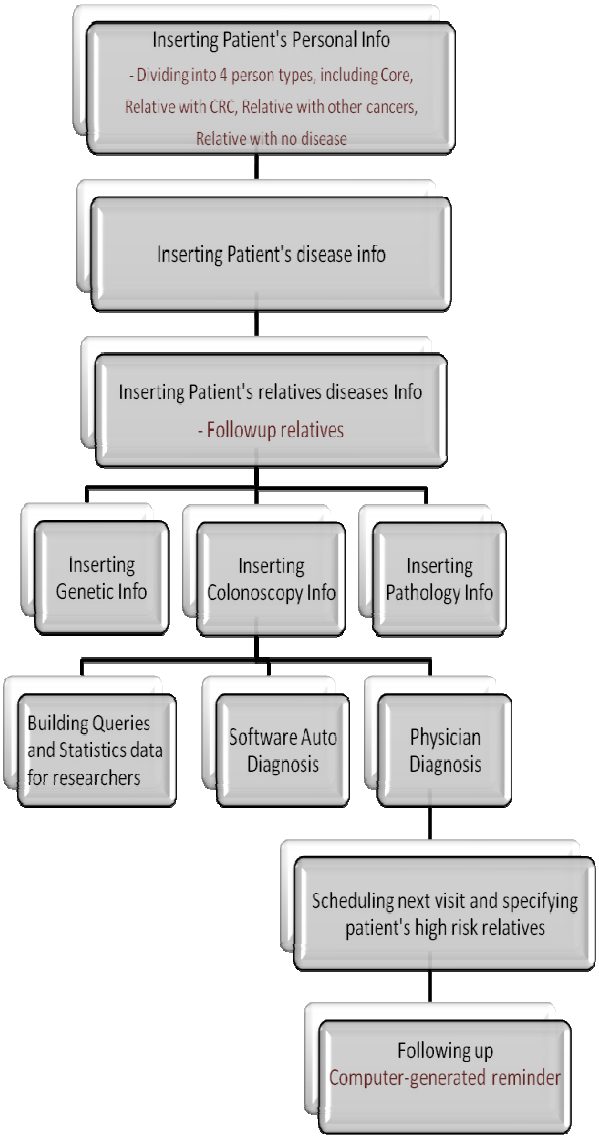

Figure 1. Flow chart of national colorectal cancer software

Table 1. Distribution of population by sex in National CRC Software

	Male	Female
Core	60%	40%
Relative with CRC	25%	75%
Relative with other cancer	50%	50%
Relative with no disease	46%	54%

STRUCTURE

The application handles the following phases of the screening process:

1. Managing the population base to be screened
2. Creating testing/screening batches
3. Storing the patients clinical information
4. Storing the pathology results
5. Storing colonoscopy results
6. Processing the results
7. Sending alerts for endoscopy, colonoscopy and other tests times.
8. Sending out screening invitations.

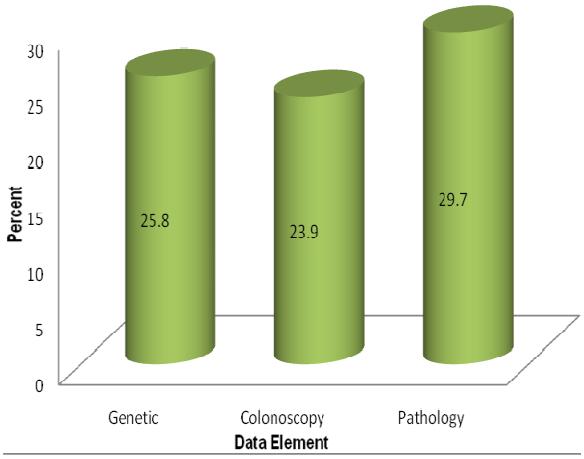

Figure 2. Data elements of software (genetic, colonoscopy, pathology)

CHALLENGES AND OPPORTUNITIES

Challenges

In order to developing this software, there were some challenges that can be divided into 3 categories: Technical Challenges, Enterprise Challenges and Infrastructure Challenges.

- **Technical challenges**

Every computer programming technique and operating system has its own advantages and limitations. It is very important to choose the best programming language and database according to the software requirements.

- **Enterprise challenges**

In medical environment, there is a relative paucity of computers and individuals with familiarity and enthusiasm for database work compared to similar sized commercial organizations.

Infrastructure challenges

Even with adequate local expertise and equipment, data transmission was limited between centers by slow internet speeds.

Opportunities:

- Analysis of information for decision making
- Improving the quality of activities via monitoring database of provinces and other center of related to national plan and feedback to them for problem solving
- Development of evidence base tools for physicians and other health care professionals
- Comprehensive information for governmental planning for better in national plan
- Cost effective manner for awareness and follow up patient and relative about preventing

CONCLUSION

CRC screening is the key solution for detecting and preventing of CRC. New technologies improve colorectal cancer screening, especially when supported by health informatics and information systems. Health informatics can effectively reduce mortality and increasing successful treatment by providing evidence – based CRC screening programs.

IS can support a national CRC screening program by facilitating the management of CRC screening by providing a database for patient identification, endoscopy and pathology results all and patient recall. In addition IS enables strategic decision making, monitoring of screening units activity and quality assurance.

The use of a comprehensive and efficient IS provides a large number of benefits for individual patients, clinicians and government departments, improving patient recall, reducing human errors and facilitating service development.

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