5th International Conference on Information Systems and Technology Management
5º Congresso Internacional de Gestão da Tecnologia e Sistema de Informação

De 04 a 06 de Junho de 2008 - São Paulo - Brasil

PS-887

INTEGRATED HOSPITAL-BASED CANCER REGISTRY SYSTEM

Zina Reis Pinheiro (Instituto Nacional de Câncer - RJ, Brasil) – zpinheiro@inca.gov.br
Antonio Augusto Gonçalves (Instituto Nacional de Câncer - RJ, Brasil) – augusto@inca.gov.br
Altino R. Leitão (Instituto Nacional de Câncer - RJ, Brasil) – altino@inca.gov.br

Hospital-based cancer registries (HBCR) collaborate to cancer research in the following areas: prevention, screening, treatment, survival, and palliation. In order to support these research efforts, the National Cancer Institute of Brazil (INCA) has developed a complete HBCR system that gathers cancer hospital registry information and consolidates data into a central cancer database. The first step of this system is done in a local server-based system distributed nationwide – SisRHC system. The cancer registries of each participating hospital enter all cancer cases with patient information and tumor characteristics. Once all information of a given year is validated, the HBCR coordinator transmits data to a centralized database – IRHC system. The junction of these two systems is called RHC Brasil and is offered by the Brazilian Health Ministry/INCA free of charge. Due to the use of these systems information is standardized assuring comparability and the high quality of information.

Keywords: cancer, registry, information system

Introduction

The National Cancer Institute (INCA) in Brazil is a nonprofit research and cancer treatment facility. In 2003 the integrated unique Brazilian health system (SUS – Sistem Único de Saúde) published 560 thousand hospital admissions. Within these admissions there were 396 thousand cases of malignant neoplasm. During the same year there were 110 thousand patients registered per month in chemotherapy and 90 thousand patients per month in radiotherapy. This type of information is needed by health authorities to develop local policies and manage resources optimally [10]. The Integrated Hospital-based Cancer Registry System allows the Brazilian Government to increase probability of survival and anticipates diagnosis in cancer and comply with recent electronic government tendencies.

Cancer registries are characterized as centers of collection, storage, processing and analysis, in a systematic and continuous form, of information on patients or people with confirmed cancer diagnosis. Cancer registries can be population based (RCBP) or hospital based (RHC). Population based cancer registries attempt to collect, process, analyze, store and interpret data of cancer cases within a specific population group (most frequently a defined geographical area). RCBP registries have hospital based registries as one of its many data inputs. Other sources of information are clinical units, national mortality database and local laboratories. Hospital based cancer registries record all cases in a given hospital, usually without knowledge of the background population; the emphasis is to serve the needs of the hospital administration, the hospital cancer program, and, above all, the individual patient [6].

The information produced in a RHC reflects the performance of the clinical body in the assistance given to the patient. The RHC aids the hospital administration to plan for annual registered and treated cases of cancer with detailed information on localization and type of tumor. They are also able to evaluate the demand and the flow of patients with cancer, by using the patient's clinical condition on entrance to the hospital. Therefore evaluating intervals of time for the diagnosis and beginning of treatment.

Research and education in a hospital unit can also beneficiate from the information on different primary localization and types of therapeutic procedures performed in the hospital. This information contributes for the development of clinical studies and epidemiologists in the hospital, and also in partnership with other institutions of research and education.
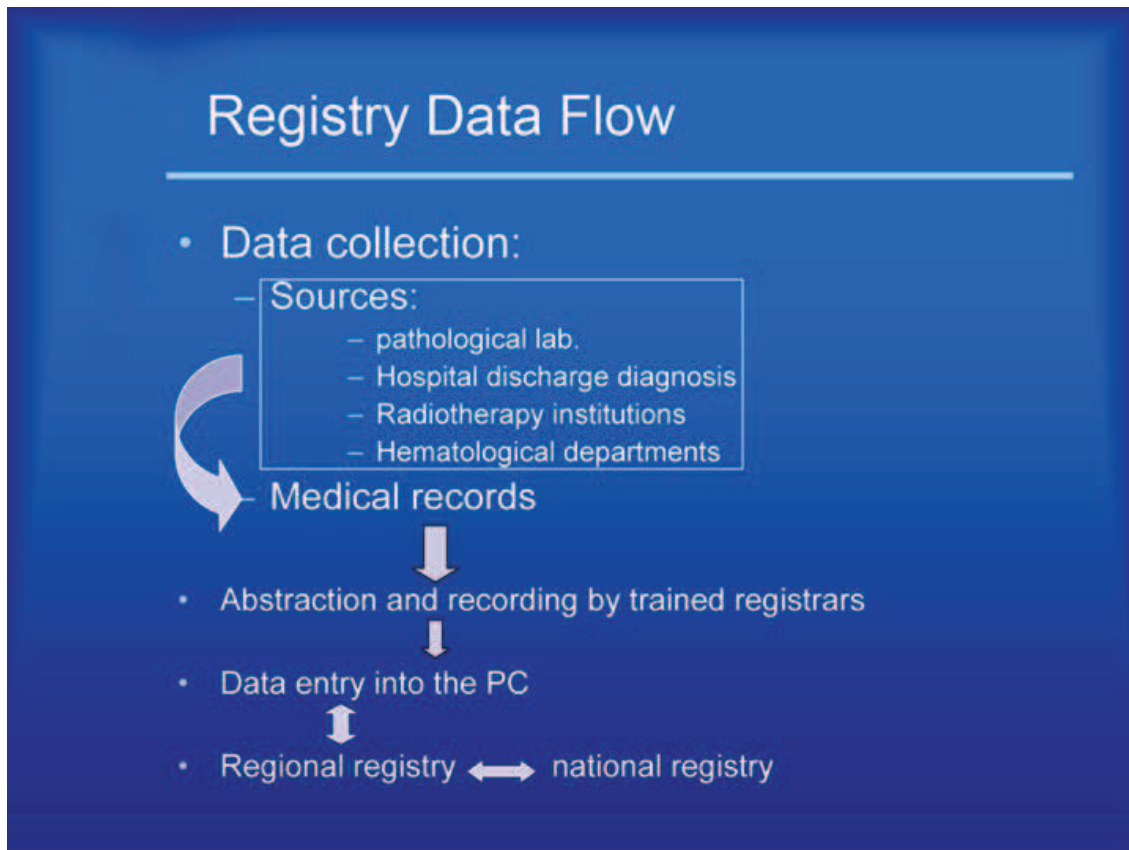
Figure 1: Cancer Registry data Flow

Methodology

Since 1983, INCA has developed a group of actions that aim in establishing a national standard hospital based cancer registry [2]. There are three steps involved in creating this national database: Hospital Based Electronic Registry (SisRHC), RHC National Database (Integrador RHC) and Publication of National RHC data. The first step is the computer application SisRHC developed by the Information Technology Department at INCA. The effort to develop this application began in 1999 where a number of stakeholder committees were established to guide INCA's IT department in the development and establish functional system requirements. Members included INCA Prevention and Monitoring of Cancer Department staff (Conprev), members of the National Brazilian Registrars Association (ABRC) and members of the three INCA cancer units (HCI, HCII and HCIII). SisRHC has since been under continuous development and deployment.

In Brazil, there are around 200 hospitals that operate a RHC. More than 100 of these registries are SisRHC users. Although SisRHC has had variations since the beginning, in its size and scope its core has been unaltered. Registries are able to deliver standardized information of all patients treated and diagnosed in a particular hospital.
Currently, SisRHC version 2.0 is a client-server system programmed in Delphi 5.0 and Firebird 1.5 as its local database. Firebird is a relational database that runs on Linux, Windows, and a variety of UNIX platforms. Firebird is completely free of any

registration, licensing or deployment fees [5]. It may be deployed freely for use with any third-party software, whether commercial or not.

The data stored in the SisRHC database comprises of patient information, diagnoses, tumor staging, information, morphology findings and cell differentiation and surgical procedures.

Currently in Brazil, hospitals that have implemented SisRHC as their electronic registry software may have all cancer registry information electronically imported into their registry databases. Despite international efforts [2] to have a complete automated cancer registry, hospitals continue to employ basically two collection modalities: automated (electronic) data and manual insertion. Automated insertion takes advantage of hospital's electronic health records for transmission of data into hospital registries. Even those hospitals that opt to use manual insertion can benefit from the electronic health record and import patient information (name, gender, date of birth, etc.) into their cancer registries.

Although importing registry information avoids duplication of effort and is cost effective, in order to insure quality of information, the registrar must analyze each case and manually enter additional tumor and diagnose information. A thorough cancer registry must examine each patient record and interpret further information through doctor annotations and exam results. Both processes are validated by automated processes and then reviewed by a qualified hospital registrar.

Histopathology data forms an important element of cancer registration and accurate, complete recording of pathology information contributes to the overall quality of a registry by facilitating high levels of ascertainment and satisfying national requirements for data completeness, including pathological staging [**Erro! A origem da referência não foi encontrada.**]. Currently data entry in most registries depends on the interpretation of free text pathology reports by trained coders – one of the many functions a professional cancer registrar. The reliability of coding is affected by the fact that pathology reports are actually intended for communication with clinicians making therapeutic decisions rather than clinical coders who work to objective rules. Free text pathology reports therefore raise data quality issues from a registry perspective because they are not designed for cancer registration purposes. In order to secure the quality of cancer registries registrars should be trained professionally.

In order to enter correctly a given cancer case the registrar must follow several validation processes. Initially the registrar validates all variables cases entered via the Registry Recording Entry Screen as in figure 2 below and/or via automated electronic hospital information system. This process includes some internal quality control systems. For example, after entry; the name, age, and diagnosis were checked visually against the received information to ensure correctness.

Figure 2: Patient Data Information Screen - SisRHC

The software program – SisRHC used since year 2000 automatically recognizes whether an individual has been registered before if the following data are identical: name; patronymic; surname; gender and birth date. In addition, the following logical checks are embedded in the program: 1) that the birth date precedes the date of diagnosis in terms of real time; 2) that the date of diagnosis precedes the date of treatment/surgery [figure 3]; 3) that gender-specific diagnoses are logical in terms of registered gender. The latter was previously done by visual checks. Visual checks were also done to look for contradictions between diagnosis and histological verification and stage, respectively. Furthermore, most data-entry fields are formatted, which ensures that impossible or undefined values cannot be entered. In fields where a numerical value represents some defined information, the field is linked to a drop-down window that depicts and explains the range of possible values that can be entered.

Figure 3: Tumor information Screen - SisRHC

Once all cases are validated coherent cases are stored in the main database and available for further searches. Incoherent cases must be analyzed individually and can be validated or remains as incoherent.

The second step of the National Hospital Based Registry is to consolidate the various hospital registries into a main centralized database. This action was initiated in 2005, gathering specifications and technology that would allow different hospitals with distinct RHC applications and technical infrastructure to integrate data.

Most hospitals that export data to centralized database are SisRHC users but this is not a pre-condition to those that wish to participate in this effort. Due to data quality and so as to minimize data deviation, there must be some attention to those hospitals that do not make use of the standard software. Non-SisRHC users are identified in the integrated database so that comparison can be made appropriately.

In order to export data to the Integrador RHC, one must download the SisRHC software or register and login to site https://irhc.inca.gov.br/ and initiate upload of data. The Integrador RHC accepts zipped files formatted by the Integrador RHC export module. This module creates a file with all variables, accepted by the Integrador RHC of all cancer registries of a pre-determined year.

The Integrador RHC treats the received data to avoid multiplicity by using comparative algorithm to identify cancer cases, registered in different cancer institutions that are possibly the same. Patients frequently migrate from one institution to another in order to have access to different treatment. When a patient enters a different institution his tumor can be registered, by mistake or as an internal standard procedure, as analytical. This means that this case will consider a tumor of a particular institution. The main objective of the multiplicity or redundant module is to elect one analytical case for the same tumor registered in different health units.

The final similarity decision is performed manually by a professional member of the INCA HBCR team.

Figure 4: Multiplicity identification Screen – Integrador RHC

The concluding phase of the National Hospital Based Registry is to make data available to the public. Consolidated data is stripped by any patient identification information, in order to secure confidentiality. The aim of RHC Brasil is to keep up-to-date and accurate information of all cancer hospital registers. Published information can be accessed on-line or downloaded into various statistic applications.
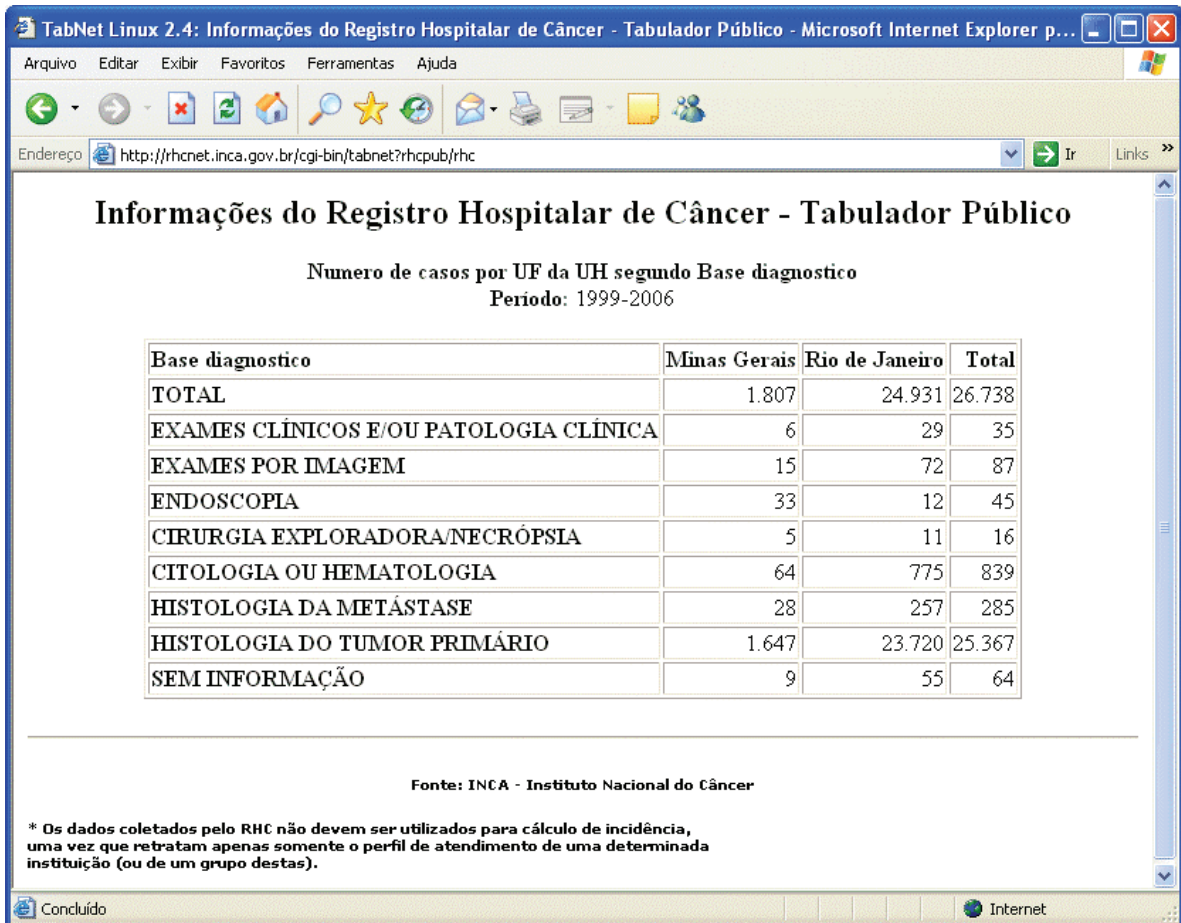
Figure 5: Public Data Tabulation for RHC data – Integrador RHC

Results

The Brazilian National Cancer Registry – RHC Brasil, collaborates to cancer research in the following areas: prevention, screening, treatment, survival, and palliation. This overarching aim of the National Registry fosters efficient and effective research on variations in cancer prevention and treatment policies and practices.

Mining RHC standardized data can be beneficial for policy makers when developing a national strategy to improve health care and disease prevention. In addition, a timely, accurate, and complete data source for clinical research will be available.

The creation of a unique cancer database will be very valuable to health managers that seek information to enhance treatment, diagnostic and cancer prevention. The ability to integrate data to have valuable information will result in a competitive advantage, enabling health care organizations to operate more efficiently.

Currently information is dispersed in many systems that can cause annoyance when data needs to be integrated. The result of this integration not only facilitates

access to information, it eliminates possible redundancy and the consolidation of various exams collected for the same patient in the national health net. There are several important steps to standardize cancer registry and allow them to coexist in the same physical space.

Since all of the information systems are developed in the same platform the challenge is to organize fields in each registry in the same database.
The central server will be located at INCA and will receive exported data and storing the information in a central database. All data is crypto graphed during the export route to insure integrity and confidentiality of the information.

Conclusion

The main goal of a cancer registry is the opportunity to disseminate information about cancer and thus initiate behavior changes in the government and general population related to cancer risk factors. Behavior is the main key to several aspects of prevention, treatment and survival [6].

The information systems offered by the Brazilian Health Ministry/INCA are distributed free of charge to users such as hospitals, government health institutions, cytology, histology and radiology laboratories. Those that accept to use these systems receive maintenance and technical updates of the registry systems and additionally access to quick information dissemination. Due to the use of these systems information is standardized assuring comparability and the high quality of information. Creation of indicators is thus easily attained in all levels from both population based and hospital based cancer registries.
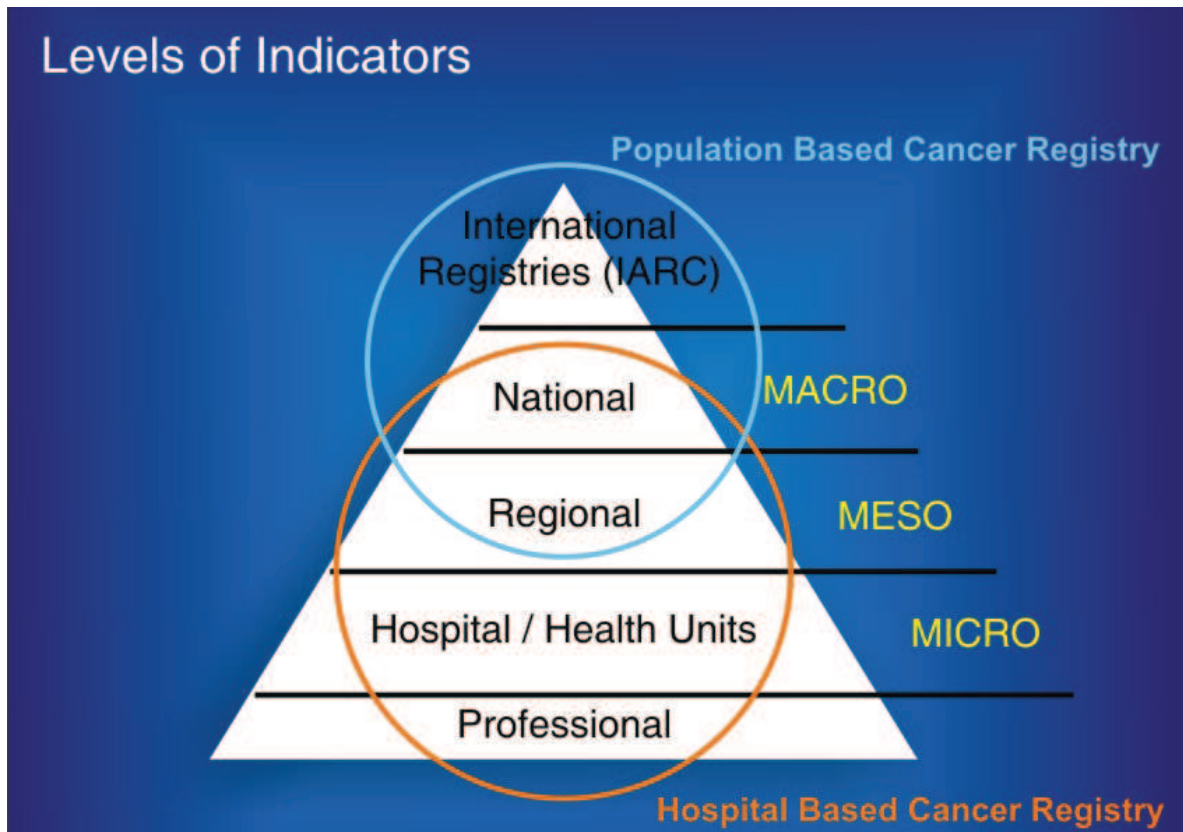
Figure 6: Indicators extracted from cancer registries

References

1. Branston, L. K.; Greening, S.; Newcombe, R. G.; Daoud, R.; Abraham, J. M.; Wood, F.; Dallimore, N. S.; Steward, J.; Rogers, C; and Williams,G. T.: "The implementation of guidelines and computerized forms improves the completeness of cancer pathology reporting. The CROPS project a randomized controlled trial in pathology." European Journal of Cancer 38 (2002) 764-772

2. Department of Health and Human Services – Centers for Disease Control and Prevention (CDC) June 21, 2007 "Modeling Electronic Reporting Project". The National Program of Cancer Registries (NPCR). Ministério da Sáude 2000. "Registros Hospitalares de Câncer – Rotinas e Procedimentos". INCA/CONPREV.

3. Graham, Amanda AL; Abrams, David B: "Reducing the Cancer Burden of Lifestyle Factors: Opportunities and Challenges of the Internet." J Med Internet Res. 2005; 7(3): e26. published online before print July 1, 2005 PMCID: 1550652

4. Hanrahan, LP; Anderson, HA; Busby, B; Bekkedal, M; Sieger, T; Stephenson, L; Knobeloch, L; Werner, M; Imm, P; Olson, J.: Wisconsin's environmental public health tracking network: information systems design for childhood cancer surveillance. Environ Health Perspect. 2004 Oct;112(14):1434-9.

5. http://firebird.sourceforge.net/

6. Miladinov-Mikov, M.: "What are cancer registries?". Med Pregl. 2004 Jan-Feb;57(1-2):27-9

7. Otter, R.; Schaapveld, M.: "Role of the Cancer Registry in Clinical Cancer Control." Presentation Comprehensive Cancer Centre North Netherlands. 2003
http://www.naaccr.org/filesystem/pdf/Annual%20Meeting%202003%20Presentation%20ROtter.pdf

8. Otter, R.; Gort, M.; Siesling, S.: "The (ir)relevance of the Netherlands Cancer Registry (NCR) in monitoring the National Comprehensive Cancer Control Program (NCCP)." Presentation Comprehensive Cancer Centre 2006

9. Peterson, MG; Rippey, RM.: A computerized cancer information system. Patient Educ Couns. 1992 Feb;19(1):81-7.

10. Rachet, B; Riga, M; Mitry, E; Romanengo, M; Quinn, M; Cooper, N; Coleman, M.: "Geographical comparisons of cancer survival indicators." Health Stat Q. 2004 Summer;(22):5-13

11. Tafazzoli, A.G.; Altmann, U.; Bürkle, T.; Hölzer, S.; Dudeck, J.: "Integrated decision support in a hospital cancer registry." Artificial Intelligence in Medicine 2002 24:3:243-255.