Hospital-Based Cancer Registry Application

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Abstract—**Previous studies on determining the most suitable cancer registration software for Indonesia find that CANREG 5 offers utmost advantage for cancer registry management. This study's aim was to actuate the implementation of this software, which development is based on recommendations from previous studies. A qualitative research method namely an experimental research was utilized in the study. For sample hospitals, there were two cancer hospitals were chosen in conducting the study. One of the two hospitals was the National Cancer Center (NCC) while the other was the Hospital for Cancer Registration Center (HCRC). The implementation of CANREG 5 consisted of three phases: (1) current technology analysis, (2) implementation, and (3) testing and evaluation. The study found that employing CANREG 5 software in a fragmented network setting was the most suitable deployment for the two sample cancer hospitals.**

Keywords—CANREG 5; cancer registry; cancer registration; application; implementation

I. INTRODUCTION

The Health Ministry of the Republic of Indonesia states that cancer is the cause of 12% of all deaths in the world, becoming the second most common cause of death right after cardiovascular disease [1]. The prevalence of tumor or cancer in Indonesia population is 4.3 per 1,000 persons. Cancer is ranked number seven in leading cause of death (5.7%) after stroke in rank number one, and followed by tuberculosis, hypertension, and perinatal [1]. In fact, cervical cancer is the most common gynecologic cancer in women [2, 3]. High rates of mortality due to cancer occur especially in the final stage of treatment. Therefore, early cancer detection can reduce mortality rate. To support early detection efforts, a few countries have a program called the National Cancer Control Program (NCCP) [4]. NCCP was created to reduce the number of deaths caused by cancers. This program also has objective to improve the quality of life for patients with cancers. Enhancing cancer registration system is one of the most important aspects of early detection efforts.

Cancer registration holds a crucial role in cancer control [5]. Its primary function is to maintain a file or register of all cancer cases occurring within a defined population. The information on cancer patients as well as the clinical and pathological characteristics of cancers would be collected and documented periodically and systematically from various data sources [5]. Data analysis would provide information on the incidence and characteristics of specific cancers in various segments of the population and within a cancer hospital's patient population. Cancer registration can also be used for monitoring occupational groups and cohorts exposed to various carcinogens and as a convenient source of data and patient sets for clinical and epidemiological studies [4]. The cancer registry can also assist hospitals in cancer patient care to provide support to clinicians for follow-ups and statistical data on therapy results. With this data, the clinicians could find the most valid and efficient way to plan and evaluate all aspects of cancer control. The main objective of a cancer registry is to collect and classify information on all cancer cases to produce statistics on the cancer occurrence within a defined population and to provide a framework for assessing and controlling the impact of cancer on the community [6].

Fortunately, the World Health Organization (WHO) has launched a software called CANREG, a cancer registration software that helps nations with the process of implementing a cancer registration system; the latest version is CANREG 5. However, the ubiquity of the open-source software does not translate to the ability for direct implementation. Each country must perform modifications based on its own needs, especially with regards to variable recording contents. A study reviewing modifications to CANREG 5 for its implementation in Indonesia has been completed [7, 8]. The focus of this previous study is to find a possible model of computer network to be developed for CANREG 5. Additionally, the study established some recommendations for the data dictionary based on information from five hospitals in Indonesia, such as the recommendation to record fifty-four variables in CANREG 5.

The CANREG 5 model has been detailed previously [7] with recommendations based on hypothetical situations. In this study, empirical findings of CANREG 5 implementation at two hospitals serve as the basis for providing more accurate guidelines on the quotidian of CANREG 5 application. With observations made from on-site implementations at the National Cancer Center (NCC) and the Hospital for Cancer Registration Center (HCRC), more definitive recommendations, such as budget and resource optimization, can be delineated, facilitating more fluid future use of CANREG 5 at other cancer hospitals in Indonesia.

A. Cancer Registration System in Indonesia

Cancer registration was developed for several decades in Indonesia. However, there was no cancer registration in Indonesia at the national level [2]. The first Indonesian population-based Cancer Registration application was

developed in the city of Semarang in Central Java in the year of 1970. Since 1987, the implementation of pathology-based Cancer Registration in Indonesia was established for thirteen areas, involving sixty-four branches of pathology laboratory in the cities such as Medan, Padang and Palembang in the island of Sumatra; Jakarta, Bandung, Semarang, Surakarta, Yogyakarta, Surabaya, and Malang in the island of Java; Denpasar in the island of Bali, Ujung Pandang (Makassar) and Manado in the island of Sulawesi. In November 2008, a newly issued regulation No. 1068/Menkes/SK/XI/2008 was declared on the topic of the Implementation of Population-Based Cancer Registration in Indonesia. The capital city of Jakarta was selected as the pilot project site conducted in forty hospitals. In 2013, several university hospitals as part of Nationwide University Network of Indonesia (NUNI) conducted a study for CANREG 5 network models for Indonesia. The purpose of this study was to analyze requirements that were necessary to implement and operate the cancer registration system using the CANREG 5 software in Indonesia, either running on a local computer or in a computer network setup [7].

B. Computerized Cancer Registration

The rapid development of Information Telecommunication and Technology (ICT) has impacted the process of cancer registration. ICT makes cancer patients' data easy to input, store, validate, and analyze. International Agency for Research on Cancer (IARC) has developed the CANREG software to help every country held cancer registration.

1) CANREG Version

Allen Bieber developed the first CANREG version. This first version was developed in DOS mode [9], marking the influence of computer operating system on CANREG development. Moreover, CANREG software was developed to fit classification systems to code the topography, morphology, and behaviour of cancer [10]. The software development also resulted in the ease of software implementation itself. Table 1 shows the CANREG version and individuals who developed the CANREG versions.

TABLE I. CANREG VERSIONS

CANREG Version	Developer
CANREG 1	Allen Bieber
CANREG 2	Stéphane Olivier
CANREG 3 and 4	Andy Cooke
CANREG 5	M. J. Ervik

2) CANREG 5 Features

CANREG 5 is an open source tool to input, store, check, and analyze cancer registry data [9]. This software can be utilized for cancer patient data entry, data validation, and analytical assistance for clinicians. The main improvements from the previous version are the new database engine, the improved multi-user capacities as well as a shift of development management similar to an open source project [11]. The main advantage of CANREG 5 is its ability to handle the new database set-up or the existing database modification through the addition of new variables and the tailoring of data entry forms [11]. This module allows individual countries to choose and define their own variables based on characteristics of interest.

CANREG 5 software was constructed for users with limited financial resources and entry-level computing skills requiring management and/or analysis for relatively small data sets [8]. This software is designed for developing countries with no cancer registration system. The advantages of CANREG 5 are [8]:

- Its customizable features that enable variable data storage as defined by users;

- Its menu language that can be adapted to the languages of the countries that use it;

- Its ability to check data duplication;

- Its automated system backup and data restoration.

CANREG 5 can be installed on any operating system platform [11], such as Windows, Apple, and LINUX. CANREG 5 was developed based on the Java language with other third-party tools to perform the analysis, consisting of [R], SOFA, PSPP, and others. One other advantage of this software is its ability to be run locally (stand-alone) or within a computer network (client-server) [9]. All of these features facilitate the ease of CANREG 5 implementation at cancer hospitals.

II. METHODS

This study employed qualitative research and experimental research methods. Two cancer hospitals were selected as the samples for this study. Both samples were major cancer hospitals in Indonesia. One of the hospitals is the National Cancer Center (NCC) and the other is the Hospital for Cancer Registration Center (HCRC).

This study was to implement CANREG 5 based on the recommendations of previous studies. The result of this study would be used to make recommendation for CANREG 5 implementation in Indonesia. Figure 1 depicts the software implementation study design in conducting the research.
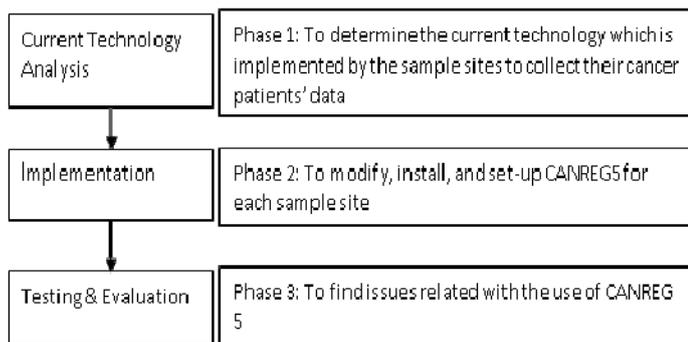
Fig. 1. CANREG 5 Implementation Study Design

III. RESULTS

A. Current Technology Analysis

1) National Cancer Center (NCC) Hospital

Cancer patient data recording for Indonesia's NCC Hospital is done by its Cancer Registration Unit (CRU). The CRU consists of ten data-entry staff and one data verification staff. The staff utilizes a standard application form that has been developed by the CRU to record data for the registry.

The NCC Hospital records its cancer patients with SRIKANDI, a software that is a modified version of CANREG 4. There are several advantages of SRIKANDI [8]:

- Its origins from CANREG 4, allowing for software customization based on cancer hospital needs;

- Its ease of operation in the Indonesian language;

- Its patient information recording based on the address format for Indonesian postal;

- Its relatively swift response when mandatory changes to the program are required.

On the contrary, there are some disadvantages of the application [8]:

- The lack of search feature for data duplication;

- The absence of an automated data checking and verification capability;

- The inexistence of security systems required to avoid unauthorized access to data storage;

- The lack of automatic data backup feature to recover data damage;

- The inexistence of an alert system for cancer patients who need follow-up treatment;

- The inability to support the process of data analysis on patient data that were stored in the database;

- The manual process of data transfer between hospitals to the cancer data center through the emailing of encrypted data.

2) Hospital for Cancer Registration Center (HCRC)

The HCRC did not have a particular division dedicated to recording its cancer patients' data. The cancer patient information was stored in the Medical Record Unit, along with information on non-cancer patients. Furthermore, data on laboratory tests were stored in the Anatomy-Pathology unit. Therefore, the clinicians and researchers found difficulties in analyzing cancer patient data from HCRC.

B. Implementation

The model of employing CANREG 5 in a fragmented network was adequate for hospitals supported with Local Area Network (LAN). The HCRC requires an application and database server for CANREG 5. Each CRU acts as a client and requires a personal computer to be installed with CANREG 5 application. For this model, CANREG 5 database setting for every CRU was to be connected to the HCRC CANREG 5 database server. Furthermore, the HCRC was requested to back-up and send file to the National Cancer Center periodically. Figure 2 shows the architecture model for running CANREG 5 in a fragmented network.
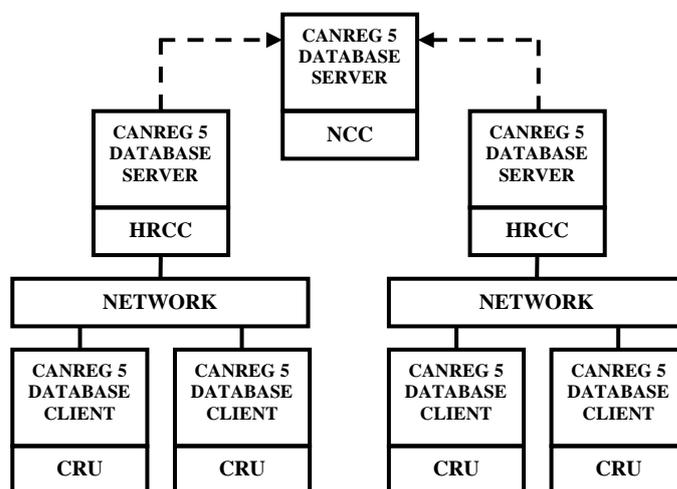

Fig. 2. CANREG 5 Architecture Model in a Fragmented Network [7]

1) Modification of CANREG 5 Data Dictionary

CANREG 5 modification process was conducted in accordance with recommendations on the design process from a previous study [7]. The Data Dictionary modification process was done by forming a variable and populating the list of choices (or Dictionary). The CANREG 5 modification process begins with the creation and defining of variables based on the fifty-four suggested variables (see Table 2).

TABLE II. VARIABLES FOR INDONESIA CANREG 5 [7]

Frame	No.	Variable	Frame	No.	Variable	Frame	No.	Variable
Patient	1	ID Number		23	Date Last Contact		31	Age
	2	MRN		24	Status		32	Address
	3	First Name	Follow Up	25	Cause of Death		33	Incidence date
	4	Middle Name		26	History		34	Diagnosis date
	5	Family Name		27	Name (Entry)		35	Topography
	6	Place of birth		28	Date of Entry		36	Morphology
	7	Birth Date		29	Name (Verify)		37	Behavior
	8	Sex		30	Date of Verification		38	Grade
	9	Race	Sources	51	Source	Tumor	39	Basis Diagnosis
	10	Religion		52	Unit		40	Extent
	11	Civil Status		53	Date of Source		41	Stage
	12	Occupation		54	Path Lab No.		42	TNM Stage
	13	Permanent Address					43	Treatment at reporting
	14	Zip code					44	Number of Metastasis
	15	Temporary Address					45	Metastases1
	16	Zip code					46	Metastases2
	17	Phone Number					47	Metastases3
	18	Age at First Diagnose					48	Metastates4
	19	Date of Height-Weight					49	Laterality
	20	Weight					50	Summary of disease
	21	Height						
	22	Admission Date						

Due to the unavailability of data, some variables were erased (see Table 3). This modification process was done by using the "Setup New/Modify Database" found in the "Tools/Database Structure" menu on the CANREG 5 application. Once the new database was established, the next stage was the Dictionary filling process for the variables.

TABLE III. UNUSED VARIABLES

Frame	No.	Variable
Patient	18	Age at First Diagnose
	19	Date of Height-Weight
	20	Weight
	21	Height

C. Installation

The installation process was performed at two hospitals, the NCC Hospital and the HCRC. The software installed was the CANREG 5 Version 5.00.31build1402, which was developed by the team led by Morten Johannes Ervik from IARC. The installer for CANREG 5 was downloaded from www.canreg.iarc.fr. The installation process consisted of two phases: the installation of CANREG 5 (on the server and client) and the CANREG 5 settings. The setting process of CANREG 5 consisted of two phases: setting the database and creating the user account.

1) Installation Process at NCC

The CRU at the NCC already possessed adequate infrastructure for the server and network system, which was originally established to run the previous cancer registration software, i.e. SRIKANDI.

The CANREG 5 was installed on the server with Windows XP version 2002 Service Pack 2 operating system. This server has Intel Xeon E3110 at 3.00 GHz speed and 4 GB of memory. The server was connected to ten units of client computers. The CANREG 5 had also been installed on the ten client computers, which were connected to the database on the computer server. Ten of the client computer consisted of five units of Personal Computers (PCs) and five units of Personal Computer (PC) Stations. All client computers were running on the Windows operating system.

2) Installation Process in HCRC

HCRC did not have a previously established CRU. Therefore, the, CANREG 5 is currently handled by the Anatomy Pathology Unit in collaboration with the Medical Records Unit. The former contributes data from the laboratory while the latter contributes other data about patients. Cooperation of the two units would serve as a temporary team to assist the CANREG 5 implementation process until a proper CRU is formed.

The CANREG 5 Server in HCRC was connected to the two client computers. One unit of the computer was in the Medical Records Unit and the other unit was in the Anatomy Pathology unit. Both the server and client are using the Windows operating system.

D. Testing and Evaluation

Testing the use of CANREG 5 could only be done at the NCC Hospital, since the NCC already had complete data sets in a standardized form. These forms simplified the data input process into the data fields in CANREG 5. HCRC could not participate in the testing process since it did not have a standard method for patient data collection; the CRU at HCRC must first develop its own data collection form before it can store data to the CANREG 5 database.

The purpose of the testing process was to determine the performance of the CANREG 5 during simultaneous execution for data entry. The test was conducted for three days by entering five hundred data forms. Table 4 shows the events during the testing process.

TABLE IV. *THE EVENTS DURING THE TESTING PROCESS*

No.	Condition	Events	Action
1	2 Unit PCs	CANREG 5 is running well	-
2	4 PCs & 4 PCs Station	When data entry is in progress, form fields are not active.	PCs station: after restart, CANREG 5 immediately returned to the last form opened. PCs: after the restart, CANREG 5 prompts for log-in.
		A few moment is needed to move to the next variable.	Wait for the log-in verification process.
3	5 PCs & 3 PCs Station	Generally, both the PC stations and PCsrun into the same problem as the previous events, but the frequency decreases.	-

Based on the results of the evaluation process, the CANREG 5 server was running slowly. The server was used for three applications simultaneously: CANREG 5, SRIKANDI, and PC Station Server; PC Station Server was suspected to be the culprit for the slow server performance.

Other problems found during the testing process were the difference in record numbers between the patients table and tumor table. The total number of records on the tumor table was 500 while the patients table indicated 503 records. The names and MRNs for those three patients were not properly entered, leading to CANREG 5's data duplication features to miss the error. Input error in the name and MRN variables were suspected due to server overload.

Duplication of data is a problem in any registration system. SRIKANDI also has a disadvantage in searching for data duplication [8]. At the testing phase, CANREG 5's feature could easily find any duplication of data, such as in the case of duplication 3 MRNs that occurred when the server was overloaded. Therefore, CANREG 5 has a better feature in data quality control, thus it guarantees the validity of the recorded data.

In the data input process, CANREG 5 provides features for data consistency checks. This is an advantage of CANREG 5 over SRIKANDI that has an issue in terms of lacking an automated the data verification process [8]. Accordingly, this feature is extremely helpful during the data entry process so it can progress quickly.

E. Conclusion

In this study, CANREG 5 was implemented at two cancer hospital sites in Indonesia to determine technical recommendations in applying CANREG 5 based on practice rather than on a hypothetical situation. Given that an open source cancer registration software intended for nationwide application has not been tested in Indonesia, assessments at a micro-scale setting is essential prior to a wider deployment of the system.

CANREG 5 was created to assist hospitals in recording and analyzing cancer patients' data. The main advantage of this software, which can be used in a variety of ICT resources regardless of the extent of its ICT supports, makes it suitable to be implemented as the Indonesian cancer registration system.

Based on the current technological analysis, utilizing CANREG 5 software in a fragmented network setting was found to be the most suitable method, as seen in its implementation at NCC and HCRC in Indonesia. CANREG 5 server also did not require a high-end computer resource. It could even be installed in low-end PC resources. The computer or the server was also installed with CANREG 5 only. Additionally, it was determined that there was a requirement for a standard application form for CANREG 5 with the purpose of assisting data entry staff with the cancer patient registration in the CANREG 5 system. In order to manage CANREG 5 continuously and adequately, it was found that NCC and HCRC should designate or establish a unit specifically dedicated to cancer registration only.

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