Brief Communication

The challenge of the implementation and evaluation of hospital-based cancer registry in Indonesia’s national referral hospital

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ABSTRACT
BACKGROUND To lower the burden caused by cancer, the Ministry of Health of the republic of Indonesia requires valid data collection to plan and evaluate cancer programs. This study aimed to evaluate the challenge of developing a cancer registry (CanReg) in Cipto Mangunkusumo Hospital.

METHODS This was an observational study on the implementation of cancer registration from the initial licensing until the creation of valid and accurate data, also the challenges in implementing hospital-based cancer registry (HBCR) in Cipto Mangunkusumo Hospital.

RESULTS Cancer registry was developed in 2016 using the 2013 Indonesian version of CanReg5 program called SriKandI. We identified some problems in this registry implementation, such as legal and human resources, medical records, electronic health records, and the CanReg5 program. Moreover, this team processed 886,086 raw patients’ data with fairly good topography and age data completeness.

CONCLUSIONS Several obstacles were encountered upon the establishment of HBCR at Cipto Mangunkusumo Hospital from program to bureaucracy and resources. Nevertheless, CanReg data can be used as a basis for decision making by stakeholders.

KEYWORDS cancer, hospitals, registries

Cancer is currently a disease that occupies the top three ranks of the highest number of diseases worldwide (incidence/prevalence). In developed countries such as the United States, cancer incidence in 2012 reached 442.88 cases per 100,000 individuals in a year where prostate cancer ranked first, followed by breast cancer, lung cancer, melanoma, and colorectal cancer.[1] Unlike in India, which is a developing country, breast cancer is the most common cancer in the country followed by cervical, lips and oral cavity, and colorectal cancer; however, only 94 cases/100,000 individuals/year are reported in India.[2] In Malaysia, which is the closest country to Indonesia, the most common cancers are lung, colorectal, and prostate cancer.[3] Based on the previous data, cancer is a major health problem in both developed and developing countries, and different patterns of cancer incidence exist for each country. A good cancer registration system is crucial so that relevant data can be used for policymaking.

The global burden of cancer estimated that cancer incidence in Indonesia has reached 134 cases per 100,000 individuals. Basic health research (RISKESDAS) in 2013 found that the cancer incidence in Indonesia was 1.4 per 1,000.[4–6] Currently, the multinational contribution data for cancer estimation in Indonesia were extrapolated by other nations with good cancer registration system.[7–10] With the high morbidity and cost burden caused by cancer, the Ministry of Health of the republic of Indonesia needs the most current and robust data to establish strategic policies that prevent increasing morbidity and cost burden caused by cancer.[11–13]

With the availability of cancer profile data, health development priorities such as the provision of labor, infrastructure, and tools can be adjusted depending on the cancer profile obtained. Similarly, in a small scope at Cipto Mangunkusumo Hospital, cancer profiles were found to be crucial to create policies in the fields of providing labor, developing rooms and equipment, and purchasing drugs. Thus, the board of directors must prioritize the allocation of appropriate budget funds to achieve such policies.[13,14] According to the Indonesian Ministry of Health Order No. 1068/Menkes/SK/XI/2008, the National Cancer Registry was established, with the pilot project conducted in DKI Jakarta Province. The outcome data would contribute to the Cancer Incidence in Five Continents Vol. X release by International Agency for Research on Cancer (IARC), but the data were rejected because of their poor quality. Hospital-based cancer registry (HBCR) in Cipto Mangunkusumo Hospital was initiated on April 2016 to improve the data quality. A joint decree about the establishment of the oncology center was officially signed by the Director of Cipto Mangunkusumo Hospital and the Dean of the Faculty of Medicine Universitas Indonesia. The cancer registration unit, where this study based, was coordinated by the oncology center of Cipto Mangunkusumo Hospital.[15] Thus, this study aimed to evaluate the challenges of cancer registry development in a hospital setting.

METHODS

This work was an observational study on the implementation of cancer registration from the initial licensing until the creation of valid and accurate data, as well as a discussion on the challenges in implementing HBCR in Cipto Mangunkusumo Hospital. This study was conducted in 2016, in accordance with the establishment of

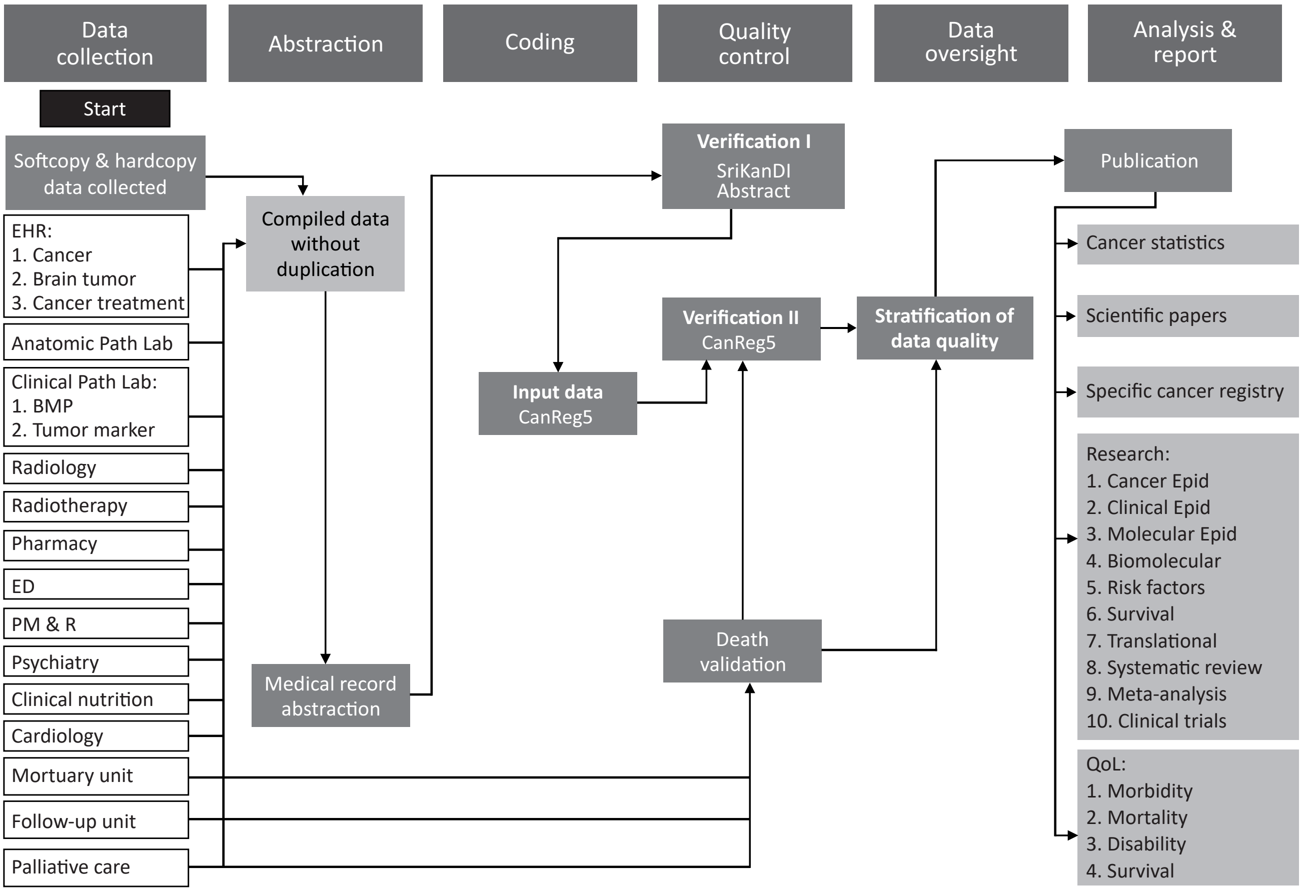

Figure 1. Technical workflow. EHR=electronic health record; BMP=bone marrow puncture; ED=emergency department; PM & R=physical medicine and rehabilitation; CanReg=cancer registry; QoL=quality of life

our cancer registry. The data provided by HBCR-Cipto Mangunkusumo Hospital comprised the population based cancer registry in DKI Jakarta and Indonesia. All sections related to the formation of cancer registration in Cipto Mangunkusumo Hospital will be part of the study. The subjects in this study were all cancer-diagnosed medical records from any department in Cipto Mangunkusumo Hospital, from January to December 31, 2013. Patients who were followed up completely before the definite diagnosis was made were excluded (follow-up was performed repeatedly until October 2016). Duplicate data were processed by manual filtering through Microsoft Office Excel software (Figure 1).

RESULTS

Cancer registry

Raw data were collected since May 1, 2016; nine registrars and an authenticator staff were recruited. Follow-up was carried out by the registrars, and the abstraction began on October 2016. Data abstraction was managed in two stages: initial filter (compile data and eliminate duplicate) and final filter (capture and recapture methods). All verification and entry processes were finished in 1 month since the abstraction began, followed by regular evaluation and monitoring by the National Controller of Cancer Registry. The Cipto Mangunkusumo Hospital Cancer Registry processed 886,086 raw data to 5,554 clean data as the final registry pooled 2013 data (Table 1).

HBCR data quality

Table 2 shows the analysis of HBCR data quality. Based on the criteria, some data did not meet the IARC “Grade A” standard. Total microscopic verification (MV) and MV without hepatocellular carcinoma was more than 75% and 80%, respectively. A small percentage of data was classified as unknown primary (0.8%), death certificate only (2.3%), and ill-defined site (0.5%). No incomplete topology and incomplete age were found.

Completeness of HBCR variables

In the analysis of the completeness of HBCR variables (Table 3), all sex and age data were found in all medical records of patients with cancer. We found that 500 addresses were missing. The most incomplete entry was cancer stage, and 2,723 (49%) cases lacked cancer stage information in their records.

Table 1. HBCR data management in Cipto Mangunkusumo Hospital in 2013

No	Departments/divisions	Raw data	Initial filter	Final filter
1	EHR			
	Outpatients	498,198	59,954	5,035
	Inpatients	34,528	6,300	-
	Support services	130,822	-	-
2	Anatomical pathology			
	Malignant neoplasms, stated or presumed to be primary; malignant neoplasms, stated or presumed to be secondary; unknown, CNS, cytology	23,974	21,016	3,085
3	Radiotherapy	1,646	-	1,646
4	Pediatric hematology			
	BMP	554	-	435
	Pediatric	2,148	1,656	283
5	Neurosurgery	732	378	113
6	Urology	82	-	82
7	Orthopedic surgery	92	-	92
8	Dermatovenerology	107	-	52
9	Ophthalmology	157	-	157
10	Gynecologic oncology	2,766	857	845
11	Radiology (2013–2014)			
	CT scan	11,902	-	1,442
	MRI	103	-	-
12	ENT	4,927	-	780
13	Neuro-oncology	870	-	870
14	BPJS/Jamkes 2013	24,091	-	-
15	BPJS 2014	147,743	-	-
16	Death certificate	644	-	525
	Total	886,086	90,161	15,442

HBCR=hospital-based cancer registry; EHR=electronic health record; CNS=central nervous system; BMP=bone marrow puncture; CT=computed tomography; MRI=magnetic resonance imaging; ENT=ear nose throat; BPJS=*Badan Penyelenggaraan Jaminan Sosial* (Indonesian Health Insurance Service); Jamkes=*Jaminan Kesehatan* (Indonesian Insurance Service for the poor and near-poor)

Legal basis

The Cipto Mangunkusumo Hospital Cancer Registration Unit is operating structurally under the Cipto Mangunkusumo Hospital Oncology Center. This is in line with Minister of Health Decree No. HK 02.02/MENKES/410/2016 concerning the Implementing Hospital for Cancer Registration and Data Control

Table 2. Data quality of hospital-based cancer registry in Cipto Mangunkusumo Hospital 2013

No	IARC parameters	Cut-off (%)	% (N = 5,554)
1	Unknown primary (C80.9)	<10	0.8
2	DCO	<10	2.3
3	Ill-defined site (C76)	<10	0.5
4	Total MV	>75	73
5	MV without HCC	>80	74.5
6	Uncompleted topology	<10	0
7	Uncompleted age	<10	0

IARC=International Agency for Research on Cancer; DCO=death certificate only; MV=microscopic verification; HCC=hepatocellular carcinoma

Table 3. Analysis of the completeness of 2013 Cipto Mangunkusumo Hospital HBCR variables

Variable	Data availability, n (%)	
	Available	Missing
Gender	5,554 (100.0)	0 (0)
Age	5,554 (100.0)	0 (0)
Patient's address	5,054 (91.0)	500 (9.0)
Topography	5,554 (100.0)	0 (0)
Morphology	4,759 (85.7)	795 (14.3)
Stage	2,831 (51.0)	2,723 (49.0)
Basic diagnosis	5,543 (99.8)	11 (0.2)

HBCR=hospital-based cancer registry

Center Hospital for National Cancer Burden.[16] The establishment of the oncology center was officially executed after a joint decree was signed between the Director of the Cipto Mangunkusumo Hospital and the Dean of the Faculty of Medicine Universitas Indonesia with the letter-number HK.02.05/XI.3/11062/2016 on April 27, 2016. One of the tasks of the oncology center based on the decree was to establish a comprehensive and continuous cancer registration system at Cipto Mangunkusumo Hospital. The Cipto Mangunkusumo Hospital cancer registration unit was formed based on the legal provisions.

Human resources

Registrars and verifiers were recruited in April 2016. Nine registrars and one verifier were recruited with Bachelor of Public Health and General Practitioner qualifications on May 1, 2016. Initial cancer registration training was carried out for the ten staff members at Dharmais Cancer Hospital on May 9–14, 2016. Further training was also conducted afterward.

DISCUSSION

The development of cancer registration faces many obstacles in the early phases. The cancer registration decision letter is still integrated with the one from the oncology center. In the future, especially when Cipto Mangunkusumo Hospital has been established as the national referral hospital for cancer registration implementation, a separate decree will help the legal basis in implementing cancer registration.

Some obstacles in Cipto Mangunkusumo Hospital's central medical record unit were inaccuracy of medical status received compared with the list of medical status ordered by the cancer registration team. Examination of the medical status received daily revealed that 40% of cases were not cancer cases. Consequently, the abstraction was not completed on time. The medical status for some patients varied. These patients had the same medical record number, so the patients were called twice.

The incompleteness of medical status was a significant hindrance for the registrar to complete the abstraction. Based on the recapitulation, 63% of the status had no national identity number of the patient written on it, the examination report was not attached, and the same medical record number was shared for different patients. The patient's name written with only one word made duplication difficult to recognize. The written medical status was often unreadable because of the poor handwriting of the medical staff. The staging was often left blank, making abstraction difficult because of many missing points.

In the electronic medical record/electronic health record (EHR), a large body of data had the International Classification of Diseases 10th Revision code for different cancers (>3) on a single medical record number, implying that the patient was diagnosed with more than three different types of cancer. Our observations on Cipto Mangunkusumo Hospital's central medical record unit strongly indicated a need for coding training and clarification for the diagnosis and staging on a patient's medical status.

Patients' medical records will be discarded after 5 years per hospital regulation; thus, some patient records were not found. Although we searched through the internal medical records of every basic data from related departments, some data were still lacking. Some departments also did not provide the full data as mentioned on the cancer registry form. Furthermore, human-related errors may occur in filtering the data due to the immense amount of data collected and manual duplicates.

From a legal aspect, we believe a separate decree is necessary as the legal basis for the implementation of a cancer registry. We recommend the implementation of an integrated EHR in the cancer registry system to simplify the diagnosis coding system and for statistical purposes. Adequate financial support and number of staff are also essential. We suggest further training in diagnosis coding and staging to the staff. If cancer registry (CanReg5) would be used, we agree with a previous publication by Godjali et al,[17] who suggested that CanReg5 must be fixed and improved. Given that this program can benefit patients, physicians, and stakeholders, we recommend the implementation of this registry system to other hospitals. Skillful human resources, legal basis, and financial support from each hospital are also essential to support the implementation and evaluation of this cancer registry system.

In conclusion, several obstacles were encountered upon the establishment of HBCR at Cipto Mangunkusumo Hospital. These problems included the bureaucracy, legal and human resources, administration, medical record status, EHR, and the CanReg5 program itself. Nevertheless, the cancer registry team processed 886,086 raw data to 5,554 clean cancer in 2013. This paper also provides insight into HBCR data in Cipto Mangunkusumo Hospital. Cancer registration data generated from this study can be used as a basis for decision making by stakeholders.

Conflict of Interest

The authors affirm no conflict of interest in this study.

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