RESEARCH ARTICLE

Surveillance Evaluation of the National Cancer Registry in Sabah, Malaysia

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Abstract

Background: Cancer is the fourth leading cause of death in Sabah Malaysia with a reported age-standardized incidence rate was 104.9 per 100,000 in 2007. The incidence rate depends on non-mandatory notification in the registry. Under-reporting will provide the false picture of cancer control program effectiveness. The present study was to evaluate the performance of the cancer registry system in terms of representativeness, data quality, simplicity, acceptability and timeliness and provision of recommendations for improvement. Materials and Methods: The evaluation was conducted among key informants in the National Cancer Registry (NCR) and reporting facilities from Feb-May 2012 and was based on US CDC guidelines. Representativeness was assessed by matching cancer case in the Health Information System (HIS) and state pathology records with those in NCR. Data quality was measured through case finding and re-abstracting of medical records by independent auditors. The re-abstracting portion comprised 15 data items. Self-administered questionnaires were used to assess simplicity and acceptability. Timeliness was measured from date of diagnosis to date of notification received and data dissemination. Results: Of 4613 cancer cases reported in HIS, 83.3% were matched with cancer registry. In the state pathology centre, 99.8% was notified to registry. Duplication of notification was 3%. Data completeness calculated for 104 samples was 63.4%. Registrars perceived simplicity in coding diagnosis as moderate. Notification process was moderately acceptable. Median duration of interval 1 was 5.7 months. Conclusions: The performances of registry's attributes are fairly positive in terms of simplicity, case reporting sensitivity, and predictive value positive. It is moderately acceptable, data completeness and inflexible. The usefulness of registry is the area of concern to achieve registry objectives. Timeliness of reporting is within international standard, whereas timeliness to data dissemination was longer up to 4 years. Integration between existing HIS and national registration department will improve data quality.

Keywords: Cancer registry - representativeness - data quality - simplicity - acceptability - timelines

Introduction

At the moment, the population-based cancer registry will not only act as information storage but is able to provide information on cancer magnitude in specified location (Parkin DM, 2006). The cancer registry as part of the cancer surveillance program should provide a focus of epidemiological expertise with the responsibility of providing data on a continuing basis on incidence, prevalence, mortality, methods of diagnosis, stage distribution, treatment patterns, and survival. It will also provide information on the risk factors for cancers of importance locally, on the prevalence of exposure to these factors in the population. Therefore it will play a crucial role in formulating the cancer control plan, as well as in monitoring its success (Parkin DM, 2008). Registry performance depends on the quality of cancer registry data and control of standard prescribed procedures. The existence of a diverse set of activities will add to the quality of the data collected and interest to the attending doctors and scholars (Storm, 1997). Among the attributes that are made by other researchers are comparability, completeness, validity of registry data and the timeliness of registry procedures (Smith-Gagen J, 2005). The evaluation has never been carried out in Sabah. This is important in its role in prevention of cancer mortality and morbidity. This also able to justify their time and efforts made by the health staff in ensuring the success of the

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system. In the end, it is a means of measuring the capability of hospitals to report within their premises.

The objectives of evaluation are to know the flow of National Cancer Registry in Sabah, to determine whether the system responds to the objectives of National Cancer Registry in terms of the surveillance's attributes and to provide recommendations for improving cancer registry and reporting systems in Sabah. In Malaysia, Non-Communicable Disease (NCD) surveillance includes components of exposure (National Health Morbidity Survey-NHMS, Global School-based Student Health Survey-GSHS, Global Youth Tobacco Survey-GYTS), outcomes (Hospital Management Information System-HMIS, death registry, disease registry) and health system response (interventions based – community, school, workplace). In Sabah, health department has established on collecting cancer data since 1999 as a regional cancer registry program by using WHO CanReg4 software program. The registry purposes are to provide an epidemiological profile of cancer, cancer burden, trends and survival, high risk groups for specific cancers and variations of incidence which may suggest clues to the causes of cancer, guided control measures and stimulate research. In 2009, the first Sabah Cancer registry 2001-2005 report was published by Sabah health department. The report provided a wide range of descriptive data on cancer trends and survival to guide health care planning and research purposes. In 2010, malignant neoplasm mortality was the fourth leading cause of death in government hospital Sabah (Sabah Health Department Facts, 2010). In Sabah, 1,501 cancer cases were identified among residents in 2007 (NCR Report, 2011). The age-standardized incidence rate for all cancers in Sabah was 104.9 per 100,000 males and 101 per 100,000 females, relatively higher as compared to national 85.1 per 100,000 males and 94.4 per 100,000 females (NCR Report, 2011). The most frequent cancers in men were cancer of the lung, colorectal, and naso-pharynx, whereas in women were cancer of the breast, cervix, colorectal (NCR Report, 2011). In 2010, Sabah consists of 3,117,405 populations and 32 ethnic groups. Sabah is the second largest states in Malaysia with 73,700 sq km. State health facilities include 24 government hospitals, 11 private hospitals, 73 health clinics and one radiotherapy service. In 2010, the ratio of doctor to population was 1 to 1864.

Materials and Methods

The evaluation is based on CDC guidelines for evaluating surveillance systems (German RR et al. 2001). In order to evaluate it, the study focuses on system attributes, data quality and feedback mechanism of the system. There are several system attributes which are pertinent to any surveillance system based on CDC guidelines. There are usefulness, simplicity, flexibility, acceptability, timeliness, sensitivity and positive predictive value (Bray F 2009). The attributes were evaluated by measuring several indicators, where applicable. The information collected consists of quantitative and qualitative data (Storm HH. 1996).

The evaluation was carried out on the National

Cancer Registry system in Sabah during the period of 1-14 March 2012. The retrospective data was traced from December 2011 until February 2012. Data was collected by documentation review, stakeholder interview, and field visits. We used self-administered questionnaires. A total of 25 respondents were involved and available in the evaluation. 4 categories of respondents were participating and actively taking part in cancer control activities. The categories from different levels were one head of department, three registrars, ten reporters and eleven data users. Few stakeholders were selected among registry staff, data users namely health educator, NCD officer, Area Medical Officer of Health and selected reporting facilities. The reporting facility was Queen Elizabeth Hospital (QEH) which contributed about 88% of all reported cases. It was the only pathology unit in Sabah to confirm cancer. Another hospital, Sabah Medical Centre was a dominant private hospital in Sabah reported about 0.85% of cancer cases.

The quantitative data was mostly on the attributes and output of the surveillance system. It was collected by using self - administered questionnaires. The qualitative data was mainly of opinion and recommendation by the implementers and stakeholders. It included interview of stakeholders and system utilizers, review of notification forms and notification records from the NCD unit from December 2011 until February 2012 and review of National cancer registry reports until 2007. Data quality was studied based on completeness category. The categories were mild incompleteness if the forms had 1-3 blank spaces for vital information, moderate incompleteness if the forms had 4-6 blank spaces for vital information and severe incompleteness if the forms had more than 7 blank spaces for vital information. Data completeness was determined for all notification forms submitted to the National Cancer Registry in Sabah during the December 2011 until February 2012. The feedback mechanism of the National Cancer Registry System was evaluated by studying State NCD meetings minutes for 2010 and availability of the National Cancer Registry Annual Report for 2007.

Results

The surveillance is was able to produce magnitude of morbidity concerned by Ministry of Health. Indicators used to determine the magnitude were Crude incidence rate (CR), Age-specific rate (AR), Age-standardized rate (ASR), Cumulative Rate (CR74), and Cumulative Risk (CumR). Detail identification of high risk group by gender, ethnicity and frequencies of cancer sites or histology information mentioned would provide information for further research and promotional activities. The surveillance was also able to provide information on cancer progression by cancer staging (57.6% at advanced stage in 2007) which was important for early detection especially for national cancer screening program and decision in hospital cancer case management. The output of surveillance was able to determine the effectiveness of existing cancer control program such as Breast Self-Examination (BSE), mammogram screening, pap

smear screening, HPV vaccination to female teenagers, quit smoking clinic and promotion of high fibre diet. Publication report as a reference to data user was National Cancer Registry Annual report 2007 and Sabah Cancer Registry Report 2001-2005.

The aim of population-based registry was to collect information on every cancer case occurring among Sabah residents. National Cancer Registry objectives are to determine the disease burden attributable to cancer by quantifying the magnitude of cancer morbidity and mortality, and its geographic and temporal trends in Malaysia, to identify subgroups in the population at high risk of cancer to whom cancer prevention effort should be targeted, to enable evaluation on the effectiveness

Figure 1. Overview Flowchart of National Cancer Registration in Sabah

Figure 2. Registry Steps

of the existing cancer control program and to stimulate and facilitate research on cancer. Case was defined as malignant in the morphology section of the International Classification of Disease for Oncology (ICD-O).).

At Sabah health headquarters, the registry is governed by one NCD officer and two clerks. The NCD officer cum public health medicine specialist is taking charged of registry since 2010. The clerks help in registering each notification in the software system and do active case finding to all hospitals in Sabah. At each notification point in hospital, the manual cancer notification is mainly done by assistant medical record officers (AMRO). The registry operation is supported by two desktop computers and printers for both clerks. The software used called CanReg4 from World Health Organisation (WHO) is installed in both computers with 24 hours internet lines. All information stored is are backed up by external hard disk sized 320Gigabyte. All printed copies are stored in the filing system and locked cabinets. The incomplete or incorrect information in the notification form will be questioned and further clarified to the respective hospital. The list of Hospital Management Information System (HMIS) of cancer data always has been checked with case notification in registry. If any HMIS cancer cases found do not match with notification in registry, an active case finding will be done by visiting 20 district hospitals every year. Notification forms have been compiled by record unit in each hospital and sent to registry in sealed envelope. The software registry is protected by password.

Upon cancer diagnosis in the ward or specialist clinic, the case will be reported by filling notification form called NCR2. The form has three carbonized copies and each copy needs to be submitted to cancer registry at health headquarter record unit in Hospital and patient's file. In the hospital's record unit, on receiving notification from the ward or clinic, assistant medical record officers will check the data completeness and compiled it in the file. The forms will be submitted to the cancer registry at health headquarter in monthly basis. In the pathology unit of QEH where all the biopsy of cancer in Sabah is centralized, dedicated laboratory officer will email the name of patient and malignancy diagnosis monthly to the cancer registry at health headquarters. At the cancer registry, the clerks as registrar will verify the data completeness. They will verify the name and NRIC in the CanReg4. If registrar do not find similar name and NRIC, it will be considered as new primary and register as a cancer case. If they find similar name and NRIC, existing case records will be updated. Diagnosis by topography and morphology will be coded by Registrar. At the end of the year, the registrar
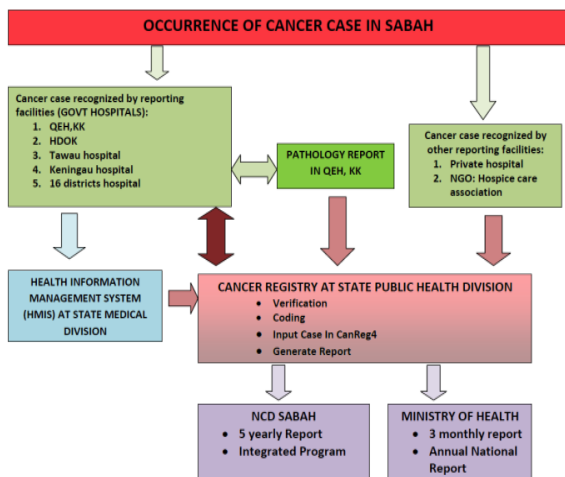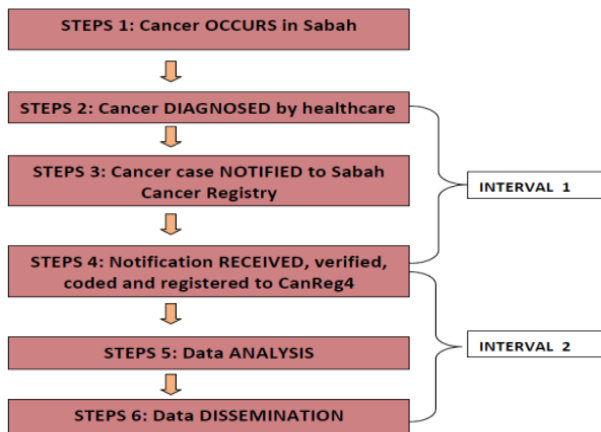
Table 1. Attributes Summary

ATTRIBUTES	RATING
Usefulness	Good to utilizers, but inadequate to achieve registry objective
Simplicity	Good (Data users), Moderate (Registrar & Notifier)
Flexibility	Inflexible
Acceptability	Moderate
Timeliness	5.7 months (Interval 1), 4 years (Interval 2)
Data Quality	63.4% (Data completeness), 3% Duplication.
Sensitivity (Case Reporting)	83.3% (Hospital Record Unit), 99.8% (Pathology Unit)
Predictive Value Positive	97.9%

will collect data from Hospital Management Information System (HMIS). The registrar has to re-abstract cancer case from HMIS and will try to match cancer case in registry. All data will be merged and sorted by notification year. In 2012, notification year data of 2008 is in the process of merging. Ministry of Health in Putrajaya had organized serial workshops to facilitate them in data analysis. The data is published in the National report 2007. In Sabah, the only report was published in 2009 as Sabah Cancer Registry Report 2001-2005 by Sabah State Health Department. There is no system integration between cancer registry and HMIS. At the moment, it is manually integrated to HMIS by annual abstraction.

The performance of registry was evaluated by assessing following attributes

a) USEFULNESS: The usefulness of registry as a surveillance was assessed by using self-administered questionnaires from 1-14 March 2012. The samples included eleven data users and three registrars. The selected data users were a deputy director, principal assistant directors, area medical of health officers and health educators. 81.8% of data users perceived that the registry was useful with ability to provide cancer trends, accessibility and risk groups. But the registrar did not aware that the registry was able to promote research as stated in the National Cancer Registry's Objective.

b) SIMPLICITY: The simplicity of registry as a surveillance was assessed by using self-administered Questionnaires from 1-14 March 2012. The samples included eleven data users, three registrars and ten reporters. The selected data users are were a deputy director, principal assistant directors, area medical of health officers and the health educators. The reporters were the assistant medical record officer from record unit and assistant laboratory officer from pathology unit in QEH. 81.8% of data users responded the registry as a surveillance was easier to access cancer information as needed. The registrars had mixed response about the simplicity at a different task. Registering notification in CanReg software was apparently easy as the variable data similar in the notification form. But the registrars had neutral easiness of getting notification from reporters because of non-mandatory notification. Registrar also had neutral easiness of doing coding from notification form to CanReg4 because the written diagnosis was general terms compared to coding in ICD-O. Registrar also had neutral easiness on doing active search at record unit in Hospital. Some of the record unit officers had not provided good cooperation. The reporter from record unit felt neutral easiness to report since they had to do double task, input into HMIS and compiling notification forms manually. They suggested cancer registry input to be integrated with HMIS. It was different from pathology unit officer, the notification was easy by emailing pathology diagnosis to registrar. Work flow of system's operation was claimed as simple, but duplication of work among AMRO at the record room made them difficult. Data analysis could only be done at ministry level. They had difficulty to analyse and needed guidance. Information dissemination was simple but limited and dependent to national publication. The latest information was available in the year 2007, and published in 2011. The factor that makes the system complicated was lack of knowledge among registrars. Simplicity of the system's structure in terms of training needs was needed. Training was needed among registrars for system coding and data analysis.

c) FLEXIBILITY: The flexibility of registry as a surveillance was assessed by using open-ended Questionnaires from 1-14 March 2012. The samples included eleven data users, three registrars and ten reporters. In pathology unit QEH, manual notification by NCR-2 was changed to email notification by monthly to registry. It was started in the past two years by pathology unit. The advantage of this electronic notification was no need for extra time, personnel or funds. The notification submitted as a case list variables similar to NCR-2 need. The innovative cancer software was created by using Microsoft Access. Ministry of health did not encourage this method since there was no guarantee of confidentiality. In record unit QEH, the registry was rigid and still had to do duplication of works between HMIS and NCR-2. They still suggested integration between both systems. In the registry, registrars admitted that there was delay in receiving notification from reporters and only be given reminder letter. There was no legal consequences for not or delay in reporting. Ease of adding or changing new definitions was not easy. Inclusion of another data in the CanReg software also was not available.

d) ACCEPTABILITY: The acceptability of registry as a surveillance was assessed by using self-administered Questionnaires from 1-14 March 2012. The samples included three registrars and ten reporters. The registrar's view of reporters' willingness to report was moderate because some of them did not understand public health importance. But registrar appeared to be acceptable to the system because they were able to complete registering in the CanReg4 system within a week. The reporter's view of willingness to report was mixed response. The reporter in pathology unit was willing to report because they had appointed one officer to take charge of emailing the results to the registrar. But reporter in record unit had moderate willingness to report because of duplication of tasks in notification and data entering HMIS. Reporter estimated that the duration from diagnosis date to reach record unit was about 2 weeks and needed another 1-month to reach registrar. The professional relationship between a reporter and a registrar was moderate mainly by phone and mail. The reminder occasionally had been given by registrar to the reporter for delaying in reporting. In summary, registrar appeared more acceptable to the registry compared to reporters.

e) TIMELINESS: The timeliness of registry as surveillance was assessed by calculating the interval between two points as interval 1 and 2. Interval 1 was defined as duration between date of diagnosis to the date of notification registered in the registry, and interval 2 was defined as duration between the dates of registered notification until date of dissemination. Date of diagnosis

meaned that incident date of patient had been seen by doctor and confirmed by pathology result. Date of dissemination was defined as National Cancer Registry Publication Date Report. The samples included all notification forms received at the registry from December 2011 to February 2012. 104 sampled notification forms (NCR-2) were selected from Government and Private Hospitals. The result of interval 1 (time until receipt) was 172 days or 5.7 months. On further questioning to the registrars, they agreed the duration of received notification until data completed and available in CanReg4 was estimated about 1 week. Whereas the reporters from record room and pathology unit in Hospital had estimated the duration of notification reached registry on diagnosis date were about 14-30 days. The delay was because of staff's ignorance on the existing system and manual forms needed. Non-mandatory notification could not be the reason for not or delay in reporting. Interval 2 (process time) was defined as duration between the date of registered notification until date of dissemination. Date of dissemination is defined as National Cancer Registry Publication Date Report. In 2011, National Cancer Registry Report was published in February. Incident cases in 2007 were reported in 2011 for planning and evaluation of Cancer Control Program in Malaysia. The estimated interval 2 was about 4 years. The delayed was because of series of time-consuming process steps to complete, including the retrieval and matching of HMIS, and the initiation of active case finding at each hospital.

f) SENSITIVITY: The sensitivity of registry to capture all cancer cases in Sabah was difficult to be calculated because of inadequate cancer information in death certificate by National Registration Department (NRD). But the proportion of registry capture the cancer cases compared to cancer cases of hospital management information system (HMIS) could be calculated, this called case reporting sensitivity. HMIS was used as a gold standard since all patients in Sabah hospital on discharge needed to be registered and coded the cancer diagnosis. The proportion of capturing the cases was divided into government hospital case reporting and pathology laboratory case reporting. Government hospital case reporting was assessed by reviewing all 2009 data in registry and HMIS. Pathology laboratory case reporting was reviewed all histopathology forms from 03 to 11 Oct 2011, serial number 14150-14700. Government hospital case reporting captured compared to HMIS showed that a total of 4613 cancer cases extracted from HMIS in 2009. 83.3% of cancer cases were captured by registry and reported as passive case detection (PCD). Pathology laboratory case reporting captured compared to cancer cases in the registry showed that 550 HPE forms from 03-11 Oct 2011 and found 99.8% were reported to registry. The obstacle to the detection of cases by registry was because of less cooperation among certain hospital staff.

g) PREDICTIVE VALUE POSITIVE (PVP): The predictive value positive meaned the number of cases in systems that were true cancer cases. Recent 104 notification forms from February to March 2012 were reviewed. A total of 104 notification forms were selected.

Five forms were excluded because four forms did not fill the morphological diagnosis and one form was without valid identification documentation. Only 99 forms were chosen as an eligible denominator. The State Consultant Pathologist was appointed to verify the morphological diagnosis of each of the 99 forms. Out of these, he identified only 97 forms had followed the case definitions. The remaining 2 cases diagnosed as Myelodysplastic Syndrome refractory leucopenia (bone marrow) and plasma cells abnormal forms. This diagnosis should not be reported as stated in the ICD-O. As summary the predictive value positive or the number of cases in systems that were true cancer cases was 97/99 x 100 = 97.9%.

h) DATA COMPLETENESS: Data quality of registry was assessed based on data completeness and potential duplication. The data was reviewed by retrospective documents assessment. Data completeness calculated by collecting 104 samples of notification forms (NCR-2) and reviewed the "unknown" or "blank" responses items and percentage of complete form was calculated. The sampling included all notification forms received at registry from Dec 2011 to Feb 2012. Data completeness of registry of each item showed 99% had filled identification card number except one case which was a foreigner. The topography of diagnosis was only filled 95.2%. This variable was an important information for tabulation of cancer site in statistics. The morphology of diagnosis was also filled about 93.3%. This had always created difficulty for coding purposes without morphology of diagnosis. Date of diagnosis was filled about 97.1%. The date was important to decide which year the incidents happened. As overall percentage of data completeness of selected items to be filled in the 104 notification forms, there was only 63.4% data completed. But the remaining 35.6% showed mild data completeness, mostly contributed by "blank" responses items of cancer stage. Potential duplication of registry was reviewed retrospective of all 2008 data. About 1450 cancer cases were selected. 3% had duplication of notification of each with similar name, identification card number and diagnosis.

Feedback Mechanism

In assessing the feedback mechanism of this surveillance system, selected 'feedback' reports were identified. These were the National Cancer Registry Report, and minutes of previous cancer control meetings. The assessment made and found one meeting minutes per year related to operation of cancer registry at state health department level. The meeting was started in year 2011, after the new principal assistant director posted to this unit. Few national cancer registry reports found and the latest was National Cancer Registry Annual Report year 2007. In 2009, Sabah health department had published the first 5-year Sabah Cancer registry 2001-2005 report. This report provided a wide range of descriptive data on cancer trends and survival to guide health care planning and research purposes.

SWOT Analysis of National Cancer Registry System in Sabah

A SWOT analysis of the system was carried out to summarize the strengths, weaknesses, opportunities and ways to strengthen the system as perceived by the researcher in studying the overall running of this surveillance system. The strengths are the NCR have a specific dedicated team for registry, uses CanReg4 software which was well used internationally, abstracting and re-abstracting system consistently applied, data user claimed it was useful and NCR have high case reporting sensitivity and predictive value positive. Whereas the weaknesses are the notification was operated manually, non-mandatory notification, duplication of tasks among AMRO in Hospital record room, moderate data completeness, and data dissemination was not timely. The opportunities for improvement included integration of HMIS with laboratory findings, to add modifiable cancer risk factor variables in the system, to start publishing and disseminating information within a year after year-end, and try to integrate National Registration Department for cancer related death data. The potential threat was a confidentiality of cancer data.

Discussion

Notification was set up in the vertical flows. Integration with other establish surveillances would lessen workload at the hospital record units. In the publication report it was able to provide magnitudes of cancer burdens, ethnicity, and gender. But it could not provide mortality ratio. It was important to determine the effectiveness of existing cancer control program. Most of the data users found the registry were useful to their needs. They could provide cancer trends, accessibility and risk groups. The usefulness might be limited to certain period and scope since the cancer epidemiology was still less priority as compared to communicable disease in Sabah. The registrar was not aware that registry can could promote research as stated in the National Cancer Registry's Objective. They were clerks who did routine manual job such as coding and registering. Probably they had less awareness because no exposure to any local cancer research in Sabah by retrieving information from the registry. They never had formal training in the past three years of cancer registry. As a host of cancer registry, knowledge of cancer should be regularly updated. Even though most of data users felt the registry was useful, in reality the objective of the registry did not achieve what had been decided. The cancer trend was not achieve within a year after year-end. The updated data could only be available after 4 years from the diagnosis year. This was also similar to the cancer risk group. Evaluation of cancer control effectiveness program could not reflect the current screening program or any health promotional activities for policy maker to make a decision. The delay most probably because of data analysis was too dependent on ministry of health which had caused delay in publication. Capacity building to do analysis needed among the registrar. Meeting of cancer related was only conducted once a year. They focused on operational issue of registry such as abstracting and re-abstracting notification at all district hospitals in Sabah. Strong commitment from respective top management in Sabah

health department would strengthen the registry. Data needed to be analysed and discussed in technical meeting with few specialists related to cancer such as oncologist, surgeon, physician etc. They also could discuss and study the effectiveness of current cancer control program timely that could be benefited to implementers and end users. Majority of the data users responded that the simplicity of registry as a surveillance was easier when accessing cancer's information as they needed. The published report was available for them to refer. The registrars had neutral easiness to get notification from reporter, to do coding and active searching. The reasons given were non-mandatory notification, lack of cooperation from reporter and written diagnosis was different from coding in ICD-O. Lack of awareness about the registry needed to be addressed by strengthening the administrative control and by serial awareness courses. The reporter from record unit felt neutral easiness to report since they have had to do double task, input into HMIS and compiling notification forms manually. They suggested cancer registry input to be integrated with HMIS. But it was different from pathology unit officers that the notification was easy by emailing pathology diagnosis to registrar. The registry is flexible in pathology unit QEH whereby manual notification by NCR-2 was changed to email notification by monthly to the registry. The notification submitted as a case list variables similar to NCR-2 need. The innovative cancer software was created by using Microsoft Access software. Integration into the cancer registry would speed up the registration. The advantage of this electronic notification was that it did not need extra time, personnel or funds. But the registry was rigid in the record unit QEH, they still had to do duplication of work between HMIS and NCR-2. They suggested integration between both systems. The registrar appeared more acceptable to the registry system compared to reporters. Reporter in record unit had moderate willingness to report because of duplication of tasks in notification and data entering HMIS. Reporter estimated the duration from diagnosis date to reach record unit is about 2 weeks and need another 1-month to reach registrar. Registrar occasionally had given the reminder's letter to the reporter for delay in reporting. Integration between HMIS and cancer registry would strengthen the notification. The perception on timeliness interval 1 was 14-30 days, but calculation of 104 samples showed median about 5.7 months to reach registry point and completed registration. This interval was comparable with International Standards set up by American College of Surgeons which specify that the cancer cases must be abstracted within 6 months from date of first contact. On further questioning to the registrars, they agreed the duration of received notification until data completed and available in CanReg4 was estimated about 1 week. Whereas the reporters from record room and pathology unit in Hospital have estimated the duration of notification reached registry on diagnosis date were about 14-30 days. That meaned that the delay most probably happened before it reached the record unit point and it could be in the ward or clinic. Opportunity to strengthen their administrative control was mainly at the primary places such as ward or clinic. Continuing courses to staff would benefit them. The

interval 2 or process time is estimated about 4 years. The delay was because of series of time-consuming process steps to complete, including the retrieval and matching of HMIS, and the initiation of active case finding at each hospital. The interval up to 4 years was considered delay compared to standard by Surveillance, Epidemiology, and End Results (SEER) program which had mentioned that registry to complete counts of new cases to the USA NCI within 22 months of the end of the diagnosis year (Clarkson LS, 2007). The delay was due to analytical process was relied on Ministry of Health's initiative including the report. State health department should analyse the data and it may shorten up to 2 years. Public health physician in the registry should be able to help the unit. Overall percentage of data completeness of selected items to be filled in the 104 notification forms it was only 63.4% data completed. More than one third had 'blank' or 'unknown' responses that was this mostly contributed by item cancer staging. Manual notification form had been filled in the ward or clinic mostly done by a junior doctor or a nurse. Inadequate supervision or lack of awareness was the contributing factor. There was no checking system at clinic or hospital level to screen the notification form. The government hospital case reporting captured compared to HMIS was 83.3% and pathology laboratory case reporting captured compared to cancer cases in the registry was 99.8%. Internal capturing data was good but the sensitivity of registry of capturing all cancer cases in Sabah could not be determined because of the data limitation from National Registration Department (NRD) of diagnosis in death certificate. The predictive value positive or the number of cases in systems that are were true cancer cases was 97.9%. The percentage was high because the reporters will would only report after getting confirmed diagnosis by HPE results. The remaining 2 cases diagnosed as Myelodysplastic Syndrome refractory leucopenia (bone marrow) and plasma cells abnormal forms should not be reported as stated in the ICD-O.

We recommend the registry to be more useful when it is fulfilled the registry objectives, and cancer data which was collected and collated able to be analysed timely by registrars. The output information needs to be discussed at State health department meeting at least twice a year, with all the medical and public health medicine specialists such as oncologist, surgeon, physician, health promotion etc. We have found the variables in the notification form only limited to patient diagnosis and treatment. Public health action will be useful if the variables in the notification include common modifiable cancer risk factors for example smoking status, alcohol consumption, fat diet, physical inactivity etc. Apart from the risk factors, patient who has been screened or intervened such as HPV vaccination, mammogram etc, registry could give information on effectiveness of cancer control program at local context. We also recommend the flow of notification should be simpler if the registry is integrated to other surveillance system. This will shorten the process time of steps to complete, including the retrieval and matching of HMIS and the initiation of active case finding at each hospital. Data in the registry need to be published within a year after year-end of diagnosis. It means current publication practice of 4 years can be reduced to 2 years. Competency courses should be given to registrar to update their knowledge. The aim is to make them understand the data use, able to make analysis and generate local report. This will make the information able to generate report timely. Data completeness will be improved if the administrator orders to all reporters that the notification from the ward or clinic must be filled completely all the variables and it must be checked by the supervisor. AMRO in the hospital also needs to check again before submission to registrar. We suggest NCD unit in Sabah health department to do regular meeting or other medium with Sabah National Registration Department (NRD). The discussion aim is to improve cancer diagnosis written in death certificate. This will increase the registry's coverage and sensitivity. Mortality ratio will able to be calculated.
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In conclusion, the performances of registry's attributes are fairly positive in terms of simplicity, case reporting sensitivity, and predictive value positive. It is moderately acceptable, data completeness and inflexible. The usefulness of registry is the area of concern to achieve registry objectives. Timeliness of reporting is within international standard, whereas timeliness to data dissemination was longer up to 4 years.

Limitation, Outpatient clinic patients are excluded because of home based case notes practice. Death Certificate Only (DCO) could not be done because of data insufficiency, so registry representativeness of true cancer cases in Sabah is impossible.

Acknowledgements

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