

Public Health Report

Quality assessment and improvement of nationwide cancer registration system in Taiwan: a review

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Abstract

Cancer registration provides core information for cancer surveillance and control. The population-based Taiwan Cancer Registry was implemented in 1979. After the Cancer Control Act was promulgated in 2003, the completeness (97%) and data quality of cancer registry database has achieved at an excellent level. Hospitals with 50 or more beds, which provide outpatient and hospitalized cancer care, are recruited to report 20 items of information on all newly diagnosed cancers to the central registry office (called short-form database). The Taiwan Cancer Registry is organized and funded by the Ministry of Health and Welfare. The National Taiwan University has been contracted to operate the registry and organized an advisory board to standardize definitions of terminology, coding and procedures of the registry's reporting system since 1996. To monitor the cancer care patterns and evaluate the cancer treatment outcomes, central cancer registry has been reformed since 2002 to include detail items of the stage at diagnosis and the first course of treatment (called long-form database). There are 80 hospitals, which count for >90% of total cancer cases, involved in the long-form registration. The Taiwan Cancer Registry has run smoothly for >30 years, which provides essential foundation for academic research and cancer control policy in Taiwan.

Key words: data quality, cancer registry, population-based system, Taiwan

Introduction

Cancer has become the leading cause of death in Taiwan since 1982 (1). To provide informative data for cancer surveillance and control policy making, a population-based cancer registry database is essential. Here, we review the establishment of Taiwan Cancer Registry (TCR) and the standardization of its registration protocol.

History and progress of nationwide cancer registry in Taiwan

The first hospital-based cancer registry was established in Taipei Veterans General Hospital in 1970. To monitor cancer incidence at national level, the TCR was organized and funded by the Ministry of Health and Welfare (MOHW) in 1979. The TCR central office has collected basic information on newly diagnosed malignant cancer

(both *in situ* and invasive cancer) patients from hospitals with >50 beds throughout the country since then. This is the short-form database of TCR.

To collect and monitor cancer registration data systematically, the TCR has commissioned to National Public Health Association (NPHA) and National Taiwan University (NTU) since 1996. The NPHA–NTU has been contracted to operate the registry and organize a Cancer Registry Advisory Board comprising 20 expert members from various fields such as pathology, clinical oncology, radiation oncology, cancer registry and public health to standardize definitions of terminology, coding and procedures of the registry's reporting system. The TCR central office is located in the NTU, and a professor of Graduate Institute of Epidemiology and Preventive Medicine heads the registry until now.

From 2002, a long-form database was established to collect more detailed information of cancer staging, first course of treatment and follow-up data in 15 hospitals with 500 or more annual incidental cancer cases for six major cancers of the oral cavity and pharynx (except nasopharynx), colon and rectum, liver, lung, breast and cervix uteri. Following the enactment of the Cancer Control Act in 2003 (2), all reporting hospitals were mandated to submit the cancer patient information to the central cancer registry office. A trace-back procedure was implemented at the same time, which has subsequently enhanced the quality of cancer registry database significantly.

Changes in registry items and data management procedures

To promote the cancer care quality, the required items of the cancer registry was extended from 20 (short form) to 65 (long form) in 2002, and further extended to 95 in 2007 and 114 in 2011 which are modified from the US FORDS (Tables 1 and 2). In 2007, 43 hospitals started to report to long-form database for six major cancers through subsidization and accreditation programs. It was further expanded to the leading cancers of both genders in 2009, including oral

cavity, oropharynx, hypopharynx, salivary gland, nasopharynx, esophagus, stomach, colon and rectum, liver, larynx, lung, breast, cervix uteri, corpus uteri, ovary, prostate, bladder, lymphoma and leukemia. A total of 80 hospitals are reporting the long-form data now. Cases reported in long-form database account for 90% of those major cancers, and the registered case number in long-form database is increasing with the decrease in the case number registered in short-form database (Figs 1 and 2). In the 114 items of long-form database, cancer site-specific factors were added to collect detailed information on laboratory values, tumor markers and other clinical information related to patient care.

There are several procedures applied to ensure the completeness and accuracy of cancer registration data of hospitals (Fig. 3). Hospitals are required to carry out a self-check procedure using standardized logic algorithms and software provided by the TCR central office to identify and correct potential errors before the data submission. The TCR central office also does the logic check of the received data before the data consolidation. Error data are sent back to hospitals for correction if any mistakes are identified.

Promotion and maintenance of data quality of cancer registration

National household registration has been implemented in Taiwan since 1906. The information on birth, death, migration and marriage is registered mandatorily and double-checked annually by household registration officers. Each citizen in Taiwan has a unique identification number (citizenship ID numbers) assigned by the household registration office. The National Health Insurance (NHI) launched in 1995 is a mandatory health insurance, which reimburses a wide spectrum of healthcares for >99% of all residents in Taiwan (3, 4). NHI provides healthcare of acceptable quality, comprehensive benefits and convenient access to treatment. In other words, diagnosis and treatment of cancer done by all general public and private hospitals are reimbursed by the NHI in Taiwan. A total of 214 hospitals with >50 beds were

Table 1. Development of Taiwan cancer registration system

Year of diagnosis	1979–2001	2002–03	2004–06	2007–10	2011–13
Long-form database					
Progress		Pilot stage	Stable stage	Extended stage	
Reporting items	–	65 items	65 items	95 items	114 items
Cancer site included	–	Required: Cervix Optional: Oral cavity and pharynx (except nasopharynx), colon and rectum, liver, lung, breast	Required: (2004 until now) Oral cavity and pharynx (except nasopharynx), colon and rectum, liver, lung, breast, cervix	Add: (2008 until now) Esophagus, stomach, bladder, prostate Add: (2009 until now) Salivary gland, nasopharynx, corpus, ovary, lymphoma and leukemia Add: (2013 until now) Larynx	
AJCC cancer staging edition	–	Sixth edition	Sixth edition	Sixth edition (2007–09) Seventh edition (2010 until now)	
Other information	–	–	–	–	Cancer site-specific factor
Reporting hospitals	–	15–17 hospitals	28–33 hospitals	43–76 hospitals	78–80 hospitals
Short-form database					
Reporting items	20 items	20 items	20 items	33 items	42 items
Cancer site included	All sites	All sites (except for six major cancers from long-form reporting hospitals)		All sites (except for the leading cancers of both genders from long-form reporting hospitals)	

Table 2. Reporting items^a collected in the cancer registry database

Item name	Short form	Long form	Item name	Short form	Long form
Reporting hospital code	○	○	TNM—Pathological stage group		○
Personal identity number	○	○	Other staging system		○
Sex	○	○	Other staging—Clinical		○
Date of birth	○	○	Other staging—Pathological		○
Age at diagnosis	○	○	Surgical procedure of primary site		○
Date of initial diagnosis	○	○	Radiotherapy target summary		○
Primary site (ICD-O)	○	○	Date of first course of treatment		○
Laterality	○	○	Date of first surgical procedure	○	○
Histology (ICD-O)	○	○	Date of radiotherapy started	○	○
Grade/differentiation	○	○	Date of chemotherapy started	○	○
Diagnostic confirmation	○	○	Date of hormone/steroid therapy started	○	○
Surgical diagnostic and staging procedure		○	Date of immunotherapy started	○	○
Tumour size		○	Date of hematologic transplant and endocrine procedure started	○	○
Regional lymph nodes examined		○	Date of target therapy started	○	○
Regional lymph nodes positive		○	Palliative care performed	○	○
AJCC cancer staging edition		○	Date of first recurrence		○
TNM—Clinical T		○	Type of first recurrence		○
TNM—Clinical N		○	Cancer status		○
TNM—Clinical M		○	Date of death		○
TNM—Clinical stage group		○	Cause of death		○
TNM—Pathological T		○	BMI/smoking/betel nut/drinking habit	○	○
TNM—Pathological N		○	Cancer site-specific factor		○
TNM—Pathological M		○			

^aMore detailed and completed reporting items information are available at the Taiwan Cancer Registry website: <http://tcr.cph.ntu.edu.tw/main.php?Page=A6>. The symbol “○” indicates the item is needed to report in the Short form or Long form database.

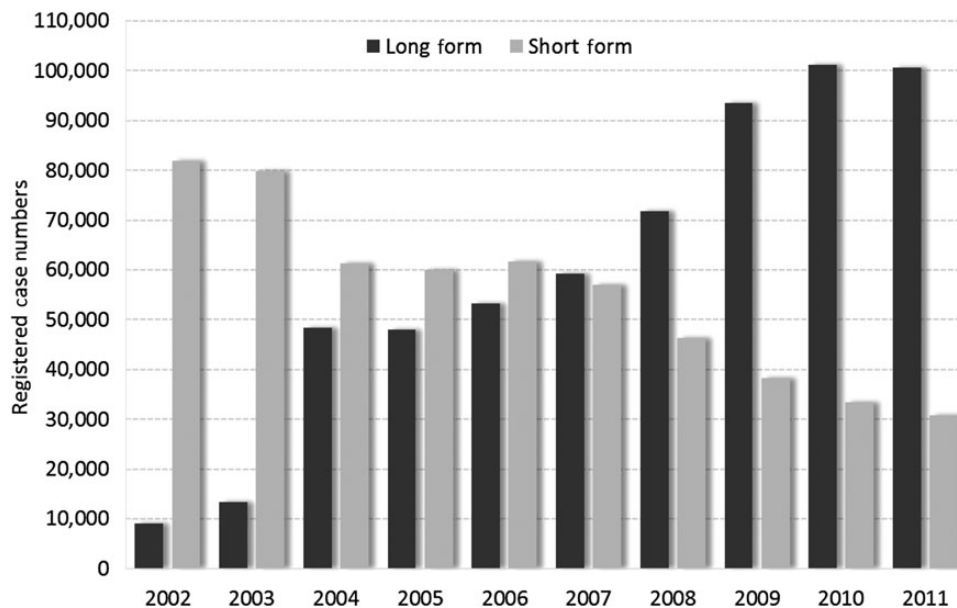


Figure 1. Registered case numbers from Long form and Short form in Taiwan Cancer Registry Database, 2002–11. The same registered case may be reported by different hospitals.

mandated to report cancer cases to TCR and 35% of them are public hospitals. As far as cancer treatment is concerned, all major medical centers have oncology departments and the specialty of oncologist requires board certification. There are 19 major medical centers and 1 comprehensive cancer hospital in Taiwan. Hundreds of regional and district general hospitals are also actively involved in cancer diagnosis and treatment.

Taiwan has several social infrastructures which allow efficient cancer registry, such as citizenship ID numbers, the National Cancer Act in 2003 which mandates nationwide cancer registration, NHI system, as well as digitized database of vital statistics, death certificates, health insurance claims and cancer screening programs. Also, the electronic medical records (EMR) have been successfully promoted for >10 years in Taiwan and used to reduce the working burden of tumor registrars

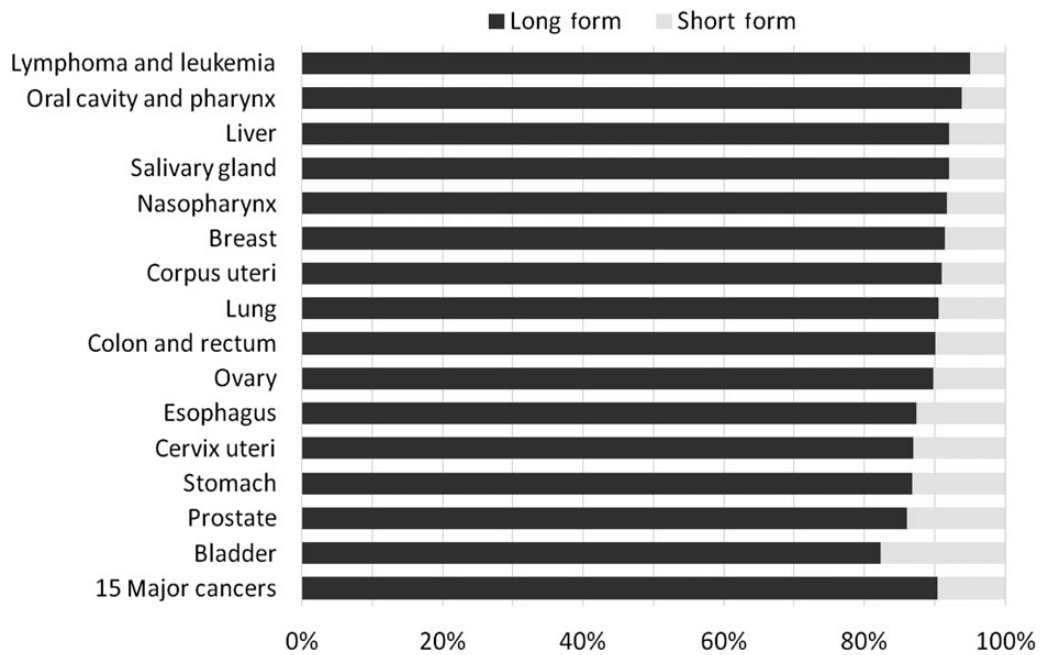
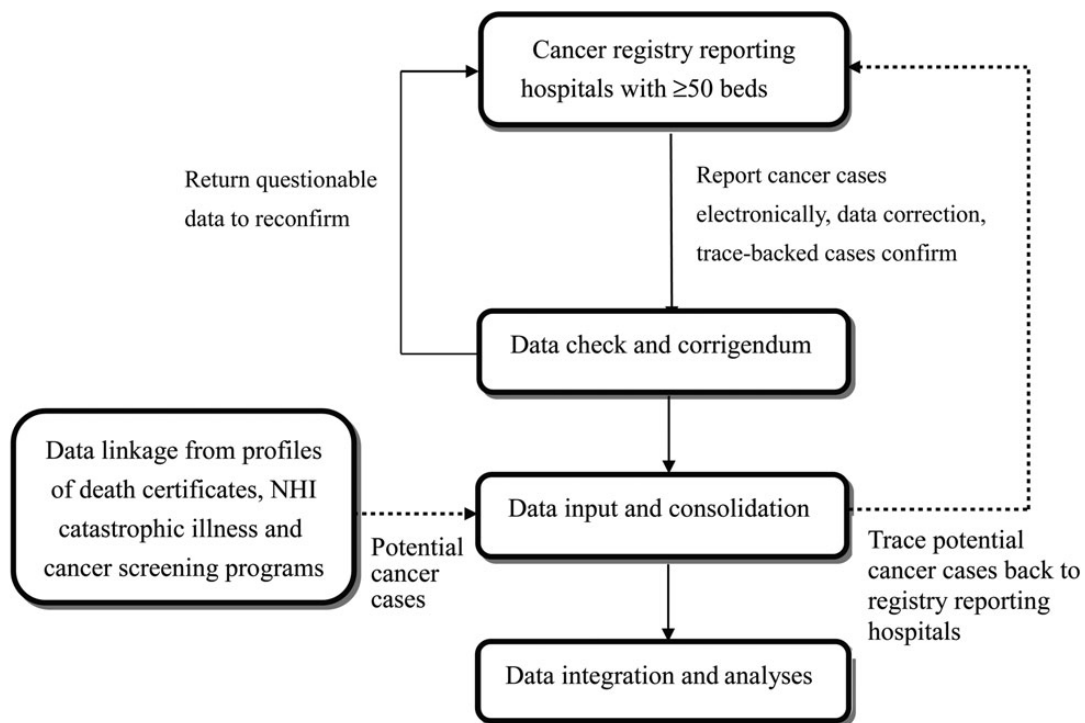


Figure 2. Percentage of registered case numbers from Long-form and Short-form Database for 15 major cancers in 2011 in Taiwan.



Taiwan Cancer Registry Center

Figure 3. Data collection and management procedure of Taiwan Cancer Registry Center.

in most hospitals. Based on these advantages, cancer registry is conducted very efficiently with excellent quality indicators in Taiwan. To improve the completeness of nationwide cancer registry, computerized data linkage with profiles of death certificate, NHI catastrophic illnesses and four cancer screening programs (data from screening programs for cancers of cervix uteri, colon and rectum, female breast and

oral cavity) is used to identify any missing cancer cases each year. Through the trace-back process, unreported potential cancer cases are traced to hospitals where the cases were cared or screened. After confirmation as missing cancer cases, they are added to the cancer registry database except cases identified from death certificate only (DCO).

Table 3. Data quality indicators of Taiwan Cancer Registry after the enactment of Cancer Control Act

Indicator ^a	Year of diagnosis									
	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Completeness (%)	92.8	95.5	94.3	96.7	97.6	97.8	97.6	97.6	97.0	97.7
Percentage of morphological verification (MV)	87.4	87.1	88.5	88.1	88.8	89.5	90.1	90.5	91.0	91.3
Mortality verse incidence ratio (%)	54.8	54.4	55.6	51.8	50.2	50.7	47.4	44.7	44.5	45.9
Percentage of death certificate only (DCO)	2.9	2.6	2.3	1.7	1.4	1.3	1.2	1.1	0.9	0.8

^aCompleteness (%): all registered cancer cases divided by all potential cancer cases from profiles of death certificate, NHI catastrophic illnesses and four cancer screening programs.

Percentage of MV: the proportion of incident cases with histological and/or cytological verification of cancer diagnosis.

Mortality verse incidence ratio (%): crude mortality rate divided by crude incidence rate of the invasive cancer during the same period.

Percentage of DCO: the proportion of incident cases with information based on DCO.

Table 4. Percentage of MV and DCO by cancer site from 2002–06 to 2007–11

Cancer site	MV%		DCO%	
	2002–06	2007–11	2002–06	2007–11
All sites combined	88.0	90.5	2.1	1.0
Oral cavity and pharynx	97.9	98.9	0.9	0.3
Nasopharynx	96.4	98.6	1.9	0.8
Esophagus	96.6	98.5	1.7	0.7
Stomach	97.2	98.1	2.3	1.1
Colon	94.7	96.8	1.9	0.7
Rectum	97.5	98.7	0.8	0.3
Liver	44.2	47.2	3.7	2.1
Larynx	95.2	97.5	1.3	0.7
Lung	90.3	93.3	4.1	1.9
Skin	98.7	98.9	0.4	0.2
Female breast	99.0	99.5	0.6	0.0
Cervix uteri	98.9	99.6	0.7	0.3
Corpus uteri	98.9	99.5	0.4	0.1
Ovary	95.3	95.0	1.2	0.9
Prostate	95.9	97.8	1.5	0.7
Bladder	98.2	98.4	1.2	0.6
Kidney	89.6	90.1	3.1	2.1
Brain and central nerve system	90.5	86.0	6.2	4.1
Thyroid	94.9	98.9	0.4	0.1
Lymphoma	97.1	97.9	1.7	0.8
Leukemia	92.5	97.6	2.3	1.5

Table 3 summarizes the percentages of registration completeness, morphological verification (MV%; the proportion of incident cases with histological and/or cytological verification of cancer diagnosis), mortality versus incidence ratio (*M/I*) and DCO% (the proportion of incident cases with information based on DCO) for all cancer sites after the Cancer Control Act was enacted (2002–11). The completeness of cancer registry database increased from 92.8% in 2002, 97.6% in 2006, to 97.7% in 2011. The MV% increased from 87.4% in 2002 to 91.3% in 2011. The *M/I* ratio decreased from 54.8% in 2002 to 45.9% in 2011. After 1985, the national death certificate database started using all residents' unique citizenship ID number to link with cancer registration data for prognosis investigation. A previous study showed the DCO% of the TCR decreased largely from 28.8% in 1985–1989 to 10.4% in 1995–1999 (5). Up to now the DCO% further decreased from 2.9% in 2002 to 0.8% in 2011. As summarized in Table 4, all sites of cancer have an increased percentage and high proportion of MV% from 2002–06 to

2007–11 except liver cancer, which diagnosis is principally based on liver images and seromarkers. The DCO% decreased from 2002–06 to 2007–11 for all cancer sites. There is a significant improvement in completeness and quality of national cancer registry following the enactment of the Cancer Control Act. The national cancer registry still continues to ensure the high data quality and effective monitoring of cancer incidence.

Establishment of the Taiwan Society of Cancer Registry and the upgrade of cancer registry database

To further standardize the cancer registry process and upgrade the quality of registry database, the Taiwan Society of Cancer Registry (TSCR) was established in 2006. The TSCR provides training, case exercises and consultation for cancer registration, and certifies basic and advanced cancer registrars, who professionalize their own career and upgrade their status and position in hospitals. In addition, the society has also trained many potential registrars and organizes them as a tutoring and auditing group. Under the governmental commission, they have standardized the novice training courses and supports to registrars and carried out the field data audit periodically through medical chart review to ensure data accuracy. They also provide services of answering questions, maintaining FAQ and designing continuous education for registrars. Both TCR and TSCR have worked closely to promote cancer registration and empower the capability of registrars in Taiwan.

The analysis of long-form data had been feedback to individual hospital performance. This feedback information may promote the data quality of cancer registration at the hospital level. Furthermore, MOHW has launched Cancer Care Quality Accreditation Program since 2008. There are five accreditation items related to cancer registration performance of evaluated hospitals. Although the accreditation program is on a voluntary basis, hospitals must pass the accreditation to become a medical center. Until now, a total of 50 hospitals have passed the accreditation, which cover 90% of incident cancer cases in Taiwan.

Future developments of cancer registry in Taiwan

A national cancer registry is essential for monitoring the cancer incidence and mortality and for developing strategies and policies to control the disease. Both completeness and accuracy are two important quality measures for registry database. They should be assessed in

the cancer registries. Taiwan has a smooth-running national cancer registry for >30 years, and the data quality of registration are gradually improved and very well regarded in last 10 years. The successful factors for improvement of the cancer registration in Taiwan may be due to the enactment of the Cancer Control Act; excellent collaboration among governmental agencies, hospitals and TSCR; and easy and free accessibility to healthcare of cancer patients.

In addition to cancer registration information, it is important to develop a health information system to provide a network of healthcare providers, governmental agencies and researchers who may contribute and share information from individual patients to ultimately improve the care of all patients by learning from the experience of others (6). The ultimate goal is to use big databases to create a platform that will assemble expertise and make cancer care more accessible to more people. Nowadays, Taiwan has lots of health information profiles, such as cancer registration data, death certificate data, NHI claim data, cancer screening data, national biobank data and so on. It is essential to integrate all these databases of diseases and wellness to provide a basis for personalized medicine, allowing healthcare to be more predictive, preventive, personalized and participatory.

In summary, the TCR is one of the high quality cancer registries in Asia and the world (7,8). The national cancer registry still continues to ensure the high data quality and effective monitoring of cancer incidence in Taiwan.

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Conflict of interest statement

None declared.

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