

Appendix 3 (d) The Department of Health—Rizal Cancer Registry

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The first population-based cancer registry in the Philippines was established in 1974 as one of the activities of the Community Cancer Control Program in the province of Rizal. The registry continues to cover 26 municipalities within an area of 1859.6 square kilometres that lie adjacent and to the east of the four cities of Metropolitan Manila. The 1980 Philippine census showed a population of 2.72 million. The estimated 1985 population was 3.5 million. From 1974 to 1979 passive data collection relied on notification from physicians and hospitals, using a form that contained 86 items of information. Data collection was rather unsatisfactory, so in 1980 active registration was started. Data sources were 61 of the biggest hospitals and death certificates obtained from 26 local civil registrars. Two registry research assistants were trained for field work and a third was assigned to input operations. A hospital abstract form containing 23 items of information and a death certificate form with 11 items of information were used.

In 1984 the registry started a cooperative activity with another population-based cancer registry, the Philippine Cancer Society—Manila Cancer Registry, which covered the four cities of Metropolitan Manila. A common hospital abstract form (see Figure 1) with 26 items of information and a death certificate abstract form (see Figure 2) are currently used by the two registries. Registry research assistants from each registry are assigned to particular hospitals, abstract data for the two populations, and subsequently exchange data, making field operations more efficient. The Manila Registry has started to computerize, whereas the Rizal Registry still employs the traditional method of manual operations using lists, files and cards. Current data sources are 98 hospitals and 30 civil registrar offices.

Case-finding

For every data source in a particular hospital, a list of cases including the patient's name, age, sex, hospital case number, date of admission/diagnosis and address (if available) is prepared. Each case-finding list is arranged alphabetically for easier matching, before abstracting. Thus for every hospital, there is a case-finding list from

medical records (in-patient and out-patient) and from departments of pathology, radiology, radiotherapy, nuclear medicine and ultrasonography. There are also lists for the specialty clinics and the Hospital Tumour Registry. These case-finding lists are helpful in collating and integrating information into the hospital abstract. The lists are also used for subsequent hospital follow-back activities.

The death certificates in the Local Civil Registry (LCR) offices of the 26 municipalities and the four cities of Metro Manila are reviewed, and for all patients who were residents of the province of Rizal, death certificates in which cancer was mentioned as an immediate, intermediate or contributory cause of death are abstracted.

Abstracting

The registry research assistants abstract hospital and death certificate data *in situ*. Harmonious relationships with hundreds of personnel, who often come and go, are quite important in this activity, which is the most difficult yet most vital step in the registration process. A hospital abstract is prepared for every primary tumour. Separate abstracts are prepared for multiple tumours.

All pertinent data which can be gathered from the different data sources within a hospital are incorporated in the hospital abstract, indicating the dates of the diagnostic procedures and the results of these procedures, in order to arrive at the most valid basis for diagnosis, topography, morphology and final extent of the disease.

Registration input procedures

All documents received at the Registry are stamped with the proper date.

Intake of cases

A summary of all cases abstracted in each hospital is prepared and this list is called the intake of cases. This list includes the hospital source, the patient's name, age, sex, address, hospital case number, incidence date and the diagnosis (topography and morphology). Cases are arranged by site and municipality. This listing will give the number of cases collected from a hospital per year, and the distribution of cases per hospital by site. It also indicates the workload of the cancer registry research assistants.

Intake of deaths

A summary of all death certificate abstracts gathered per municipality per year is prepared and is called the intake of deaths. This list includes the place of death and the person who signed the death certificate, the patient's name, age, sex, address, date and cause of death. Cases are arranged by site. This list gives the number of deaths from cancer per municipality per year and the distribution of these cases by site. It also provides the cases for follow-back and the hospitals where the follow-back is going to be made.

Appendix 3(d)

RIZAL MEDICAL CENTER CANCER REGISTRY
 RIZAL MEDICAL CENTER
 Pasig, Metro Manila
 POPULATION BASED REGISTRY FORM

(2) PATIENT REGISTRY NO.

(20) MULTIPLE PRIMARIES

1. First Primary
 2. 2nd Primary
 3. 3rd Primary
 etc.

(79) NAME OF HOSPITAL

(14) HOSPITAL CASE NO.

(4) NAME OF PATIENT Last Name First Name Middle Name

FOR MARRIED WOMEN: MAIDEN NAME:

HUSBAND:

(5) SEX 1. Male 2. Female 9 Not Stated

(9) MARITAL STATUS

1 Never Married
 2 Married
 3 Widower
 4 Separated/Divorced
 9 NS

(11) AGE (AT INCIDENCE DATE)

00 Less than 1 year
 99 Not Stated

(8) PERMANENT ADDRESS (See Separate Code)

YEARS: (Actual Number)

00 Less than 1 year
 99 Not Stated

CITY ADDRESS

(6) DATE OF BIRTH

Day Mo. Yr.

(11) PLACE OF BIRTH (See Separate Code)

(54.) RACIAL GROUP (See Separate Code)

INFORMATION SPECIFICALLY STATED

0 Not Stated
 1 Stated

(54.2) DIALECT GROUP:

(13) INCIDENCE DATE

Day Mo. Yr.

(17) MOST VALID BASIS OF DIAGNOSIS:

- | | | | |
|-----------------|---|-------------|--|
| NON-MICROSCOPIC | | MICROSCOPIC | |
| 1 | Clinical Only | 5 | Cytology Hematology |
| 2 | Clinical Investigations | 6 | Histology of Metastasis |
| 3 | Exploratory Surgery/Autopsy | 7 | Histology of Primary |
| 4 | Specific Biochemical and or/
Immunologic | 8 | Autopsy with Concurrent or
Previous Histology |
| | | 9 | Death Certification Only |

(18) PRIMARY SITE (TOPOGRAPHY) _____

(19) HISTOLOGICAL TYPE (MORPHOLOGY) _____

(23) FINAL DESCRIPTION OF EXTENT OF DISEASE (AFTER SURGERY/AUTOPSY)

- | | | | |
|---|------------------------------------|---|--|
| 1 | In Situ | 6 | Distant Metastasis |
| 2 | Localized | 8 | Not Applicable (For sites other
than breast, lung & Cervix and
for cases diagnosis clinically) |
| 3 | Direct Extension | 9 | Unknown |
| 4 | Regional Lymph Node
Involvement | | |
| 5 | 3 4 4 | | |

(24) PRESENT STATUS

- 1 Alive
- 2 Dead

(26) CAUSE OF DEATH

a _____
b or c _____

(25) DATE OF DEATH

Day		Mo.		Yr.	

(27) RESULT OF AUTOPSY

- | | | | |
|---|----------------------|---|------------------------------|
| 1 | No Autopsy | 6 | Case Found at Autopsy |
| 2 | No Residual Tumor | 7 | Diagnosis Not Confirmed |
| 3 | Primary Site Revised | 8 | Autopsy Done, Result Unknown |
| 4 | Morphology Revised | 9 | Unknown if Autopsy Done |
| 5 | Diagnosis Confirmed | | N/A |

(83) PLACE OF DEATH

Hospital _____
Home _____

SOURCE OF DATA

- 1 Hospital
- 2 Death Certificate (LCR)
- 3 Both

REPORTED BY: _____

DATE OF REPORTING: _____

Figure 1. Example of the registration form used by the Rizal Medical Center

Check for completeness and consistency of documents

Both the hospital abstracts as well as the death certificate abstracts are checked for completeness. The registry research assistants are advised to write N/S for information not specified and N/A for information not applicable. Essential data are

—malignancies usually seen in adults such as epithelial neoplasms of the breast, lung and cervix reported in children.

Documents with inconsistencies are held in the suspense file pending correction.

Hospital and death certificate abstracts with incomplete or inconsistent essential data are held in this file pending completion of information and correction of errors. The file is arranged alphabetically for easier management. The cases in the suspense file are followed back in the hospital sources and the research assistant makes the correction in the abstracts. This file is usually processed in batches.

Record linkage

The registry maintains a master patient index file (MPIF) which is composed of index cards of all registered cancer cases, arranged alphabetically, and including both living and dead cases. Each index card in the MPIF contains the following items of information: patient's name (surname, first name, middle or maiden name), patient registry number (PRN), age, sex, address, data source, hospital case number, incidence date or dates, primary site or sites, morphology and, if applicable, the date, place and cause of death.

The completed hospital abstract is matched with the MPIF and the file of prior to reference date cases (FPRDC) as to name (surname, first name, and/or middle name or maiden name). In matching the name, allowance is made for errors in spelling (phonetic spelling of names or errors in spelling owing to varying degrees of legibility of handwritten hospital records). Matching with the MPIF determines whether the patient has been registered or not. If there is a similarity in name, the age, sex, address and diagnosis are compared.

Case accession or updating

If the case has not previously been registered, a new patient registry number (PRN) is assigned, and an index card for the MPIF is prepared and filed. The case is then entered in the accession register, and the assigned PRN is added to the intake of cases for the appropriate hospital. The case is also entered in the site accession register. The clerk in charge of the input operations verifies that the PRN is on all documents and then proceeds to code all data on the hospital abstract. The abstract now becomes a tumour record which is filed numerically according to the PRN.

If the case has previously been registered (old patient), the new abstract is compared with that of the previous tumour record, to determine if this is a new primary or not. If this is a new primary tumour, the existing PRN is assigned. This PRN is indicated in the intake of cases in red ink. The accession register and the index card of the MPIF are updated and the new primary tumour is listed in the site accession register. Verification procedures ensure that all documents have the correct PRN and all data are coded. This tumour record is filed with the previous tumour record of the patient, based on the assigned PRN.

If this is not a new tumour, the existing PRN is used and the accession register and the index card of the MPIF are updated. The existing PRN in the intake of cases is

indicated in red ink. Verification ensures that all documents bear the assigned PRN. All data are coded and filed with the previous tumour record, based on the assigned PRN.

If it is not certain whether or not this is a new primary tumour, and additional information is necessary, the abstract is held in the suspense file until the information becomes available.

Abstracts of death certificates

The completed abstract of death certificates is matched with the MPIF to determine if the case has been registered previously. If the case has not been registered previously (new case) and the patient died in the hospital, the case is followed back at the specified hospital and a hospital abstract is prepared. If the case has not been previously registered and the patient died at home, the death certificate abstract is matched with all case-finding lists from the different hospitals to determine if the patient had been seen in a hospital or not. If the name of the patient appears in these lists, the case is followed back at the specified hospital, and a hospital abstract is prepared. If the patient has not been previously registered and cannot be followed back or traced back to a hospital or the physician who signed the death certificate, the case is registered under the category of 'death certificate only' (DCO). In this case, a new PRN is assigned, and the index card for the MPIF is prepared and filed, the case entered into the accession register and the PRN indicated in the Intake of Deaths. The patient is then listed in the Site Accession Register.

Because of an initially high rate (25–30%) of cases registered under the DCO category for the years 1977 to 1982, it was decided to make a more intensive follow-back of cases notified only in this way. From 1983, death certificate abstracts were collected before hospital visits so that potential DCO cases could be followed back immediately at the initial visit to the hospital. Repeat hospital follow-back is done whenever necessary.

If the case has been registered previously, the death certificate is matched with the previous tumour record. If this is the same tumour, the existing PRN is assigned and indicated in the intake of deaths, and flagged with red ink. The index card of the MPIF and the accession register are updated. The abstract is filed with the previous tumour record.

If the case has previously been registered but a different diagnosis is given, the death certificate abstract is compared with the previous tumour record and, if necessary, follow-back at the hospital where the patient died is carried out to rule out a new primary tumour. It should be pointed out that death certificates signed by physicians other than the attending physician may not be accurate, since they often rely on second-hand information furnished by the patient's relatives.

Coding

From 1978 to 1982, nine items of information were coded on special coding sheets. These were: age, sex, municipality, incidence date, basis for diagnosis, topography, morphology, behaviour and date of death. From 1983, coding was done in the hospital

abstract. For recorded tumours from 1978 to 1982, the topography and morphology were coded according to the 1975 Revision of the International Classification of Diseases (ICD-9). Starting in 1983, coding for topography, morphology and behaviour was based on the International Classification of Diseases for Oncology (ICD-O). Coding is done mainly by the registry research assistant responsible for input operations under the supervision of one of the consultants of the registry. Problematic cases which cannot be resolved are taken up in regular meetings with the other members of the registry staff. Coding is checked to ensure that the codes used are valid and the codes are recorded in the appropriate boxes. Itemized coding instructions are written and revised when needed.

Maintenance of records

The registry keeps the following records: *abstracts*—hospital abstracts and death certificate abstracts; *lists*—case-finding lists, intake of cases, intake of deaths, accession register, and site accession register; *files*—suspense file, master patient index file (index cards), and file of prior to reference date cases (index cards).

Sorting and merging

The data files are arranged in a particular order to meet the needs of the registry. Since they have been arranged in a specific order, subsequent cases registered should also follow the same order of filing. The MPIF and the FPRDC are arranged alphabetically. The tumour records are filed numerically, according to the PRN. The site accession register is filed according to site, municipality and hospital for each year.

Editing

Checking for completeness, legality of codes and inconsistencies is carried out manually, before, during and after entry into the tumour file.

Updating the existing tumour record

The existing tumour record is updated by correction of errors or by addition of previously missing information. Such items may include a new primary tumour, a more definite topography, morphology or final extent of disease, a more valid basis for diagnosis or details of the patient's death—cause, date and place of death.

Storage

The tumour records are kept in folders containing 100 documents each, arranged numerically, according to the PRN. The index cards of the MPIF and the FPRDC are kept in boxes arranged alphabetically in a filing cabinet.

Retrospective checking for duplicates

Some duplication of registration may occur in the following cases. The same patient may use different names such as the use of the maiden name in one hospital and the

married name in another. Some patients use nicknames or aliases, as in the case of some Chinese patients. There could have been errors in the spelling of the patient's name which may not have been noticed during matching with the MPIF. Inaccurate information like date of birth or place of birth may lead to the belief that there are two patients when in fact there is only one.

When duplication is discovered, all existing records are drawn together to update one tumour record and cancel the other. Records are filed with the PRN given earlier. The cancellation is recorded in the accession register.