STANDARD PROCEDURE MANUAL

(version III)

for Population-Based Cancer Registries in sub Saharan Africa

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on behalf of African Cancer Registry Network

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African Cancer Registry Network (AFCRN)
International Agency for Research on Cancer (IARC)
American Cancer Society (ACS)
Union for International Cancer Control (UICC)

GLOSSARY

AFCRN	African Cancer Registry Network
AJCC	American Joint Committee on Cancer
CI5	Cancer Incidence in Five Continents
EARN	East African Cancer Registry Network
IACR	International Association of Cancer Registries
IARC	International Agency for Research on Cancer
ICD-O	International Classification of Diseases for Oncology
INCTR	International Network for Cancer Treatment and Research
NAACCR	North American Association of Central Cancer Registries
NGO	Non-governmental organization
NOS	Not otherwise specified
PBCR	Population-based cancer registry
UICC	Union for International Cancer Control
WHO	World Health Organization

BACKGROUND

Cancer is public health problem in both developed and developing countries as a result of the increase in life expectancy, changes in diet, lifestyle and other factors. To help address this growing burden in some African countries, the Cancer Registry Programme of the International Network for Cancer Treatment and Research (INCTR) established the East African Cancer Registry Network (EARN) which later became the African Cancer Registry Network (AFCRN) in 2012. The overall aim of the network is to improve the effectiveness of cancer registration and surveillance in sub Saharan Africa by providing expert evaluation of current problems and technical support to remedy identified barriers, with long term goals of strengthening health systems and creating research platforms for the identification of problems, priorities and targets for intervention. The AFCRN serves as the "regional hub" of the Global Initiative for Cancer Registration (GICR) of the International Agency for Research on Cancer (IARC). Sub-Saharan African countries, like countries in other regions, urgently need these data for cancer control planning, intervention programmes and subsequently for the use by Health Ministries, policy makers, researchers, clinicians, Non-governmental organization (NGOs) and other stakeholders. All countries should have at least one population-based cancer registry, for the purposes of setting priorities, targets for interventions, and monitoring success of cancer control.

INTRODUCTION

This manual provides a model, or template, for a Standard Procedure Manual for cancer registries of sub-Saharan Africa. It provides a guide for registry staff in the processes needed to register cancer cases (case finding, abstracting, coding, data entry and storage). Most of the definitions and coding schemes are from international handbooks and guidelines, particularly those published by the International Agency for Research on Cancer (IARC), the International Association of Cancer Registries (IACR), and the Union for International Cancer Control (UICC).

Since every registry is different, some sections are provided only as instructions, guidelines, or examples. **These are shown in blue font, *with* or without *italics***. Each registry will have to customize these sections for their own use. The items of information that are described in the manual (for abstracting from medical records, coding, and entering on the computer) correspond to the AFCRN minimum data set. It is recognized that some registries will wish to collect more than this (for example, patient occupation, co-morbidity, morphological grade).

At the present time (2015) the great majority of African cancer registries still use traditional manual procedures to collect information on cancer cases – that is, entering the required items of information onto a paper form, which is then coded, and entered into a computerized database. In a few instances, the data sources being used (hospitals, laboratories, death registration systems) have their own computer database, which can be used to directly transfer the required data to the registry. However, in this manual, the emphasis is on the manual methods, with reference, where appropriate, to more automated techniques.

3. CASE FINDING

3.1 SOURCES OF INFORMATION (where to collect data)

All possible sources of cancer information for the registry should be identified. The main sources of information are hospitals, pathology laboratory reports, radiology departments, medical records, death certificates, postmortem/autopsy reports, and radiotherapy and oncology units. However, a registry may also cover private clinics and general practitioners, hospices and screening programmes to ensure completeness.

A list should be prepared for each of the data sources in a hospital to facilitate case finding. The registry should maintain a log book indicating sources covered and when they are covered. Ideally a registry should have a data collection time table indicating frequency of visits to various sources. This monitors the completeness of case finding.

Data sources in hospitals

Use all available sources to ensure the collection of most cases, including those diagnosed clinically (no histo-pathological confirmation), and those that were diagnosed histologically.

I) Medical records: out-patients and in-patients records, admission and discharge forms or books.
- *If there are discrepancies between the diagnosis on admission and that on discharge, the discharge diagnosis is preferred.*

II) Pathology records: pathology reports, autopsy reports and cytology and haematology reports

III) Radiology records: CT scan reports, MRI reports, Ultra sound reports and mammography reports

IV) Radiotherapy department

V) Oncology department

VI) Mortuary register

VII) Disease index (in medical records department)
- *This may be a card index or a hospital information system on computer. However, the disease index may be incomplete, so the registry staff should attempt to cover all available data sources in order to achieve complete registration.*

Other sources

These include: hospices (VERY useful), health insurance systems, screening programmes and central registries.

Death certificates

Are death certificates mentioning CAUSE of death available?
- *In the hospitals?*
- *In civil registration (births, marriages, deaths) offices?*

If they exist, they should be used as a source if at all possible.

3.2 REPORTABLE LIST

What cancer cases should be reported to the registry?

All **cancer cases**, in persons who are **resident** in the ***[Registry Area]***[1] diagnosed since ***[date]*** must be reported to the registry.

Cancer cases include:

- Cases considered as malignant in the morphology section of the International Classification of Diseases for Oncology (ICD-O); behaviour code-3 should be reported to the registry.
- Benign tumours and tumours of uncertain behaviour of the brain (behaviour code-0, 1, 2).
- Carcinoma *in situ/* cervical intraepithelial neoplasia grade III (CIN-3) of the cervix (behaviour code-2).

Cancers in metastatic sites (for example, lymph nodes) are common, especially in pathology reports. These cases should be registered with the tumour site ("topography") = the site of the primary tumour. If this is not known, register as "unknown primary site" (see section 4.4.3, page 15).

ALL cancer patients, no matter how they were diagnoses, must be reported, including patients with a clinical diagnosis of cancer based only on clinical judgment.

All cancer cases diagnosed at autopsy must be reported.

Patients with active disease and a history of cancer must be reported.

Unclear terms may be found in case notes or laboratory reports, when the physicians are not sure about the behaviour of a tumour (usually when no histological examination has been done). The following table provides some guidance as which should, or should not, be registered.

Accept As Cancer	Not Cancer (Not Reportable)
• Apparently (malignant) • Presumed (malignant) • Compatible with (malignancy) • Probable (malignancy) • Suspect or suspected (malignancy) • Suspicious of (malignancy) • Most likely (malignant) • Consistent with (malignancy)	• "Rule out" • "Equivocal" • "Possible" • "Suggestive" • "Questionable" • "Very close" • " Approaching" • " Encroaching upon"

In cases where the diagnosis remains doubtful, the details should be abstracted but kept in a pending file.

Resident

A person is normally considered a resident in the registry area if they have lived there for *3/4/6/12 months.* Temporary residents – for example, those coming into the area for medical treatment (often lodging with relatives) – must be excluded.

[1] *The registry may decide to register ONLY cancer cases normally resident in the "target population" of the registry, OR to record all cases traced in the sources of information being used, and sorting residents from non-residents at the time of analysis of the registry database*

HOWEVER, it is difficult to apply this *x month* rule unless the cancer patient is interviewed.

Normally, we rely on “place of residence” as recorded by staff in the admissions/medical record office. These staff should be encouraged to enquire about the true/usual residence (and not just the temporary “contact” address).

4. ABSTRACTING

Abstracting is the process of extracting from various source documents the information needed to make a registration of cancer.

4.1 REGISTRATION/NOTIFICATION FORM

In paper-based abstracting, the information is entered onto a REGISTRATION/NOTIFICATION FORM (Fig 4.1)

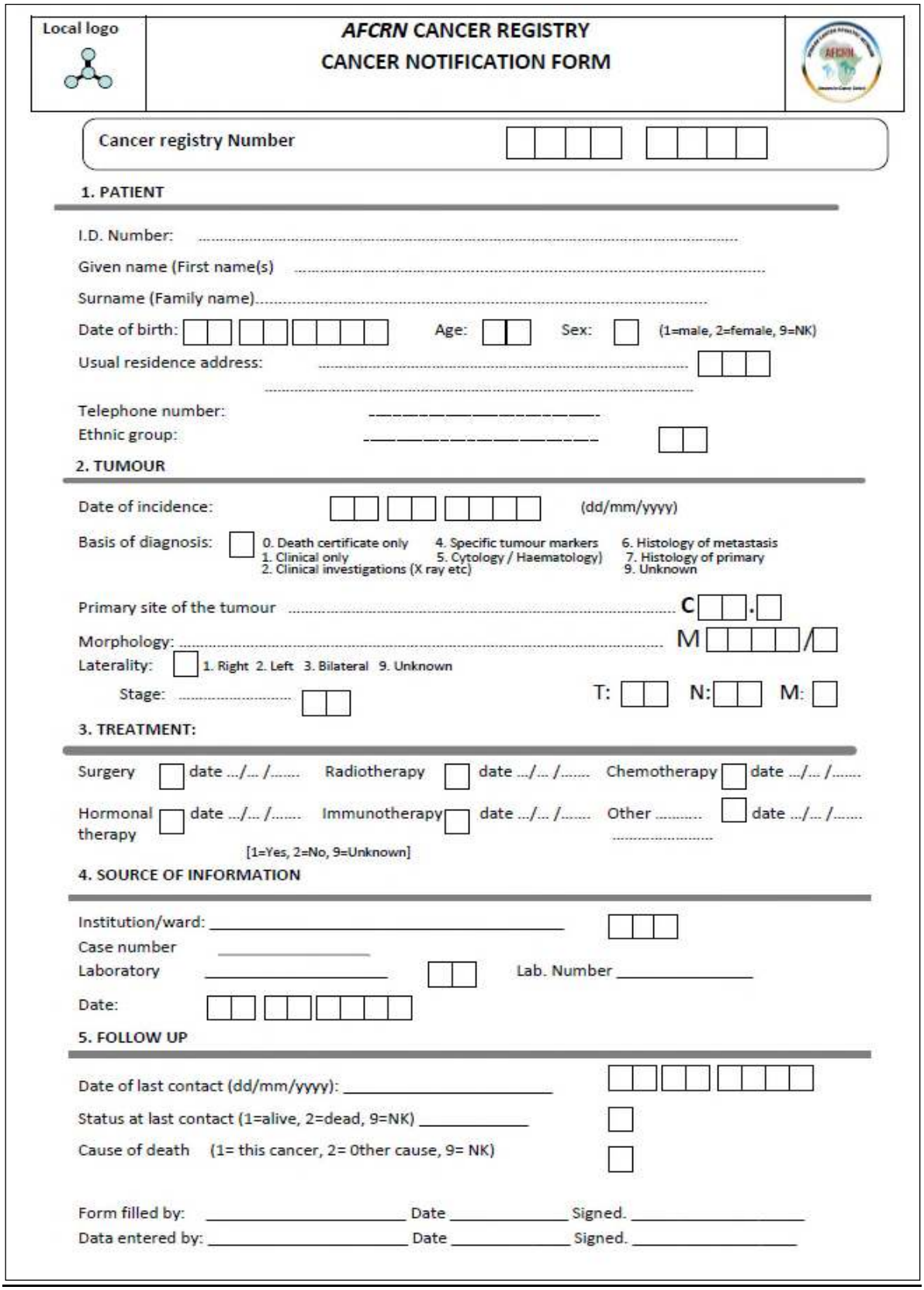
Check before abstraction onto the form

- Is the diagnosis reportable?
- When was the incidence date?
  - Was the incidence date on or after [reference date of the registry]?

COMPLETE A REGISTRATION/ NOTIFICATION FORM EACH TIME A REPORTABLE CANCER CASE IS FOUND IN ANY OF THE INFORMATION SOURCES YOU ARE USING

The different variables that are collected are divided into:

- **Mandatory variables**: These MUST be completed, or a record cannot be confirmed in CanReg. They are: patient names, usual residential address, age, sex, incidence date, most valid basis of diagnosis, primary site, histological type, and behaviour
- **Optional variables**: Telephone number, ethnic group, laterality, stage, TNM, grade, treatment, follow-up status (date of last contact, vital status)



Local logo

***AFCRN* CANCER REGISTRY**
CANCER NOTIFICATION FORM

Cancer registry Number ☐☐☐☐ ☐☐☐☐

1. PATIENT

I.D. Number: .....

Given name (First name(s) .....

Surname (Family name).....

Date of birth: ☐☐ ☐☐ ☐☐☐☐ Age: ☐☐ Sex: ☐ (1=male, 2=female, 9=NK)

Usual residence address: ..... ☐☐☐

.....

Telephone number: _____

Ethnic group: _____ ☐☐

2. TUMOUR

Date of incidence: ☐☐ ☐☐ ☐☐☐☐ (dd/mm/yyyy)

Basis of diagnosis: ☐ 0. Death certificate only 1. Clinical only 2. Clinical investigations (X ray etc) 4. Specific tumour markers 5. Cytology / Haematology) 6. Histology of metastasis 7. Histology of primary 9. Unknown

Primary site of the tumour ..... C☐☐.☐

Morphology: ..... M☐☐☐☐/☐

Laterality: ☐ 1. Right 2. Left 3. Bilateral 9. Unknown

Stage: ..... ☐☐ T: ☐☐ N:☐☐ M: ☐

3. TREATMENT:

Surgery ☐ date .../... /..... Radiotherapy ☐ date .../... /..... Chemotherapy ☐ date .../... /.....

Hormonal therapy ☐ date .../... /..... Immunotherapy ☐ date .../... /..... Other ..... ☐ date .../... /.....

[1=Yes, 2=No, 9=Unknown]

4. SOURCE OF INFORMATION

Institution/ward: _____ ☐☐☐

Case number _____

Laboratory _____ ☐☐ Lab. Number _____

Date: ☐☐ ☐☐ ☐☐☐☐

5. FOLLOW UP

Date of last contact (dd/mm/yyyy): _____ ☐☐ ☐☐ ☐☐☐☐

Status at last contact (1=alive, 2=dead, 9=NK) _____ ☐

Cause of death (1= this cancer, 2= 0ther cause, 9= NK) ☐

Form filled by: _____ Date _____ Signed. _____

Data entered by: _____ Date _____ Signed. _____

Fig 4. 1 The AFCRN Cancer Registration/Notification Form

4.2 DEATH CERTIFICATES

For death certificates, look at the section related to "Cause of Death", page 24. A typical section of a death certificate – the part where causes of death are written – is shown as Fig 4. 2. Note that the doctor can write several medical conditions – those that lead to the death, and those that might have contributed to it.

COMPLETE A CASE REGISTRATION/NOTIFICATION FORM FOR PERSONS WITH CANCER MENTIONED ANYWHERE ON THE CERTIFICATE

Cause of death		Approximate interval between onset and death
I Disease or condition directly leading to death*	(a)	.....
	due to (or as a consequence of)	
Antecedent causes Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last	(b)	.....
	due to (or as a consequence of)	
	(c)	.....
II Other significant conditions contributing to the death, but not related to the disease or condition causing it	.....	.....
	.....	.....
**This does not mean the mode of dying, e.g. heart failure, respiratory failure. It means the disease, injury, or complication that caused death.*		

Fig 4. 2 International Form of Medical Certificate of Cause of Death

4.3 MULTIPLE PRIMARIES

The cancer registry counts tumours not persons. Cancer patients may develop independent cancers in their lifetime. Before registering a case as a new tumour, consider:

- Is the lesion an extension, or metastasis of an existing tumour?
- Is it a recurrence[2] of an earlier tumour?

If the response to the above questions is "NO", it should be considered a new primary and a separate registration/notification form should be prepared, including morphology, behaviour, basis of diagnosis etc.

When the data are entered into CanReg, the user will be asked to confirm whether the tumour is a new primary or an extension or recurrence of an existing cancer. The rules of the International Agency for

[2] When cancer returns after a period of remission, it is considered a "recurrence". A cancer recurrence happens because, in spite of the best efforts to treat or clear off cancer, some cells remain. These cells could be in the same place where the first cancer originated, or they could be in another part of the patient's body. These cancer cells may have been dormant for a period of time, but eventually they continued to multiply, resulting in the reappearance of the cancer.

Research on Cancer (IARC) and the International Association of Cancer Registries (IACR) are used by CanReg (IARC Internal Report No.2004/02, http://www.iacr.com.fr/images/doc/MPrules_july2004.pdf). These rules were developed for international comparisons when reporting cancer incidence and survival. They are reproduced in detail in Appendix 1.

USE ONE CANCER REGISTRATION/NOTIFICATION FORM FOR EACH PRIMARY TUMOUR DIAGNOSED.

4.4 THE VARIABLES TO BE RECORDED ON EACH CASE

Mandatory variables (must be abstracted) in red

4.4.1 CANCER REGISTRY NUMBER (CRN)

A unique number assigned by the registry to each patient. This number is written on all documents and items of information relating to the patient. The first four digits of the CRN are usually the year when the patient was registered.

Example: 2015- 0001 is the CRN assigned to the first patient registered in 2015.

[CanReg-5 automatically allocates a "patient number" to all records of the same individual. It does not have to be recorded on the registration form]

4.4.2 PATIENT INFORMATION

ID number

Record the personal identification number (the national identity number, social security number) which is unique to the individual, whenever it can be found.
Abstract in detail the complete number, including any check digits when they exist.

Names

Whenever possible:

- Give the full names of the patient
- They should be recorded as first name/personal name
- Followed by family name

For married women who have taken the name of their husband:

- The family name of the husband should be used.
- The patient's maiden name (unmarried name or name at birth) should be indicated under the heading 'Maiden name"

Titles such as Dr, Reverend, El Haj, etc. should be

- Entered on AFTER the first name, like this: Beatrice (Sister); Peter (Prof.) ….

Date of birth

When present in the record, enter as day, month and year (dd/mm/yyyy). If any part of this information is not known, record as unknown or not specified (e.g. 99/99/2014).

Age

This refers to the age in years at the incidence date (see below). It MUST be recorded, as the patient's age on his/her last birthday; do not round of to the next birthday.

- If the birthdate is known, check whether the given age is correct or not.
- Infants aged less than 12 months of age, record as 00.
- For persons aged 98 or MORE, record as 98.
- If not possible to find the age, enter 99 (age unknown).

Sex

Enter as 1 for male, 2 for female.

If the sex is not recorded, this may be inferred from the given name[3] and from the wording of the hospital summary. In very rare instances, the sex cannot be determined or there may have been a sex change. This information should be recorded.

Usual residence address

Record as much detail as possible of the patient's usual residence. Ideally this should include the number, street, city or municipality, province and country residence. The usual residence is where the patient would be counted, if a census took place.

It **MUST** be distinguished from the patient's temporary address at the time of admission, for example a patient from the country may come to the city for medical treatment and stay temporarily with friends or relatives. His/her address in the country is the permanent address and the address in the city is the temporary address. Record the person's country of birth if this variable is required.

Telephone number

Record all the telephone numbers (fixed line, mobile phones) of the patient **AND** that of the next of kin.

Ethnic group

Indicate to which ethnic group (tribe, or language group) the patient belongs.

There may be some problems in classifying individuals of mixed heritage. Record all the details. When abbreviations are used in the medical record, be sure to know exactly what the abbreviations mean.

4.4.3 INFORMATION ON THE TUMOUR

Date of incidence

The date of the first event (of the six listed below) to occur chronologically should be chosen as incidence date. If an event of higher priority occurs within three months of the date initially chosen, the date of the higher priority event should take precedence. Order of declining priority:

1. Date of first histological or cytological confirmation of this malignancy (with the exception of histology or cytology at autopsy). This date should be, in the following order:
    a date when the specimen was taken (biopsy)
    b. date of receipt by the pathologist
    c. date of the pathology report
2. Date of admission to the hospital because of this malignancy.
3. When evaluated at an outpatient clinic only: date of first consultation at the outpatient clinic because of this malignancy.
4. Date of diagnosis, other than 1, 2 or 3. It may be date of first clinical investigation procedure fort the malignancy e.g.: MRI reports, CT scan reports etc.
5. Date of death, if no information is available other than the fact that the patient has died because of a malignancy.
6. Date of death, if the malignancy is discovered at autopsy.

Whichever date is selected, the date of incidence should **NOT** be later than the date of the start of the treatment, or decision not to treat, or date of death.

[3] The fact that some names are unisex should be taken into consideration.

Basis of diagnosis

The medical records should be studied carefully to determine the different methods used to confirm the diagnosis of cancer. The most valid basis of diagnosis or the most conclusive method of confirmation should be noted down on the abstract. If additional information becomes available later, the most valid basis for diagnosis should be updated.

The suggested codes (Table 4.1) are hierarchical, so that the higher number represents the more valid basis, and should thus be used for this purpose. If there is no information on how the diagnosis had been made (information obtained from an automated source, for example) the code 9 (Unknown) should be used.

Code 0 is used for Death Certificate Only – that is, cases registered for which the only available information on cancer was on a death certificate, and where follow-back attempts have been unsuccessful. This category does not include cases first coming to the registry's attention by means of a death certificate mentioning cancer for which other bases of diagnosis became available.

Code 6 should be used when a histology examination has shown cancer to be present – but the specimen examined contained a metastasis, and was not from the site of origin (primary site) of the tumour. This is often the case when the specimen is a lymph node.

CODE	DESCRIPTION	CRITERIA
0	**Death Certificate Only**	The only information to the registry is from a death certificate.
Non Microscopic		
1	**Clinical**	Diagnosis made before death, but without the benefit of any of the following (2-7)
2	**Clinical investigation**	To include all diagnostic techniques, including x-ray, endoscopy, imaging, ultrasound, exploratory surgery (e.g., laparotomy) and autopsy, without a tissue diagnosis.
4	**Specific tumour markers**	To include biochemical and/or immunological markers which are specific for a tumour site (Table 4.2).
Microscopic		
5	Cytology	Examination of cells whether from a primary or secondary site, including fluids aspirated using endoscopes or needles. Also to include the microscopic examination of peripheral blood films and trephine bone marrow aspirates.
6	Histology of a metastasis	Histological examination of tissue from a metastasis, including autopsy specimens.
7	Histology of a primary tumour	Histological examination of tissue from the primary tumour, however obtained, including all cutting techniques and bone marrow biopsies. Also to include autopsy specimens of a primary tumour.
9	Unknown	

Table 4. 1 IARC - IACR Basis of Diagnosis Codes

Specific tumour markers	
Human Chorionic Gonadotrophin (HCG)	In diagnosis of choriocarcinoma (usually >100,000 iu in urine)
Prostate Specific Antigen (PSA)	In diagnosis of prostate carcinoma (usually >10 µg/l serum)
Alphafetoprotein (AFP)	In diagnosis of hepatocellular carcinoma (usually >200 ng/ml serum)
Catecholamine degradation products (HVA, VMA)	In diagnosis of neuroblastoma
Elevated serum immunoglobulins	Myeloma (IgG >35g/l or IgA > 20g/l) Waldenström's macroglobulinaemia (IgM > 10g/l)
Urinary immunoglobulins	Myeloma (light chain excretion > 1g/24hr)

Table 4. 2 Specific Tumour Markers

Primary site

Carefully review all reports contained in the clinical record and record the site in which the tumour originated. The primary site may at times be determined by a pathologist reviewing tissue from a secondary site (e.g. a primary carcinoma of lung diagnosed by excision and microscopic review of lymph nodes). It is also possible to deduce a primary site from the determination of a specific morphology (e.g. a nodular melanoma of the neck indicates a malignancy of the skin of the neck). [See RULE H (site associated morphology), in the ICD-O coding section, page 29].

Sites such as 'head', 'thorax', 'limb', 'pelvis', and ‘abdomen’ are poor descriptors of site, since a tumour may arise in a number of tissues (skin, soft tissue and bone) within these sites. It is important to extract all the diagnostic information available in the record.

If there is no mention of the primary site in the record, but a secondary site(s) has been identified, note all available information regarding the secondary site(s) – **BUT DO NOT CODE OR ENTER THE SECONDARY SITE INTO THE COMPUTER**. The information on the primary site may be added at a later date if it becomes available.

Morphology

In abstracting histology, record the complete histological diagnosis as stated in the pathology report's Final Diagnosis. Do not modify the pathologist's final diagnosis by picking up descriptive terms found in the microscopic description of the tissue.

If conflicting statements exist regarding the diagnosis, prefer statements from the pathology reports over other statements.

If the histological diagnosis is stated using only non-specific terms such as 'malignant neoplasm’, ‘cancer' or ‘malignant tumour', abstract these terms until more detailed information becomes available.

Behaviour

The behaviour of a tumour is the way it acts within the body. The behaviour of the tumour is coded as the 5th digit of the morphology code (after the "/"). Table 4.3 shows the spectrum of behaviours. A tumour can grow in place without the potential for spread (/0, benign); it can be malignant but still growing in place (/2, non-invasive or in situ); it can invade surrounding tissues (/3, malignant, primary site).

Behaviour codes /6, malignant, metastatic site, and /9, malignant, uncertain whether primary or metastatic site, must not be used.

Always enter the PRIMARY site (with /3 to indicate a malignant tumour). If the site of the primary cancer is unknown, this should be noted and the appropriate ICD code will be given C80.9 (unknown primary site).

Code	
/0	Benign
/1	Uncertain whether benign or malignant
	Borderline malignancy
	Low malignant potential
	Uncertain malignant potential
/2	Carcinoma in situe
	Intraepithelial
	Noninfiltrating
	Noninvasive
/3	Malignant, primary site
/6*	Malignant, metastatic site
	Malignant, secondary site
/9*	Malignant, uncertain whether primary or metastatic site

* Not used by cancer registries

Table 4. 3 Behaviour codes (ICD O-3)

Laterality

This should be recorded for all paired organs, but as a minimum for lung, breast, eye, ovary, testis and kidney.

Stage

Record **stage of disease** as it is found in the case record.
If it is present, record the staging system that was used:-

- FIGO - Female reproductive site cancers was developed by the International Federation of Gynaecology and Obstetrics.
- DUKE's - The Duke's staging system is a classification system for colorectal cancers.
- UICC/AJCC stage is also widely used.

Unless you have been trained and are authorised to do so, **DO NOT** assign stage to a cancer if it is not noted in the patient's medical records.

TNM

The extent of disease should be recorded in terms of the three digit code of the TNM system. The rules for coding according to the TNM system are described in TNM Classification of Malignant Tumours, 7th Edition, 2009 (Sobin, Gospodarowicz and Wittekind).

The TNM system is not used for the coding of the extent of lymphomas, leukaemias, brain tumours and childhood cancers (defined as < 15 years of age at diagnosis).

Staging should be done at the time of initial diagnosis. It is based on information that can be either clinical (c), which is the stage before any treatment, or pathological (p), which is the post-surgical histo-pathological classification.

In the absence of surgery, staging is based upon examinations carried out prior to medical treatment, or radiotherapy, or during the hospital stay when these treatments were started, or a decision made to withhold them.

The detection of metastatic disease **after** the first course of treatment (including during adjuvant treatment or hormonal therapy) does **NOT** change coding of extent of disease at diagnosis.

pTNM vs. cTNM

When the stage/extent of the cancer is recorded in the clinical and/or pathological records according to the TNM system, these codes should be registered.

Record stage from pathology - pT (rather than cT) and pN (rather than cN), if they are available.

When T, and/or N, and/or M have not been explicitly recorded in the clinical/pathological records, the cancer registrar should attempt to score extent of disease according to the Essential TNM scheme. (see section 5.7. Page 31)

4.4.4 TREATMENT

Record any treatment described in the patients' records initiated within 4 months from incidence date. This includes therapy given at the reporting hospital as well as those given in other facilities. Treatment is considered as a specific therapy which controls or destroys cancer tissues both at the primary and metastatic sites. **Cancer-directed treatments** include surgery, radiotherapy, chemotherapy, hormonal therapy, immunotherapy and palliative care. Also record any other care that the patient received.

Record the **DATE** on which each of these treatments was started.

Surgery

It is total or partial surgical removal of the tissue of the primary or the metastatic sites. It is performed most of the time after diagnosis.

Radiotherapy

Include external or beam radiotherapy, or internal radiation.

External radiotherapy uses X-rays from cobalt or linear accelerator machines, electrons, and more rarely other particles such as protons to destroy cancer cells in the treated area by damaging the DNA within these cells.

Internal radiation A source of radiation is put inside the body. One form of internal radiation therapy is called brachytherapy**,** where the radiation source is a solid in the form of seeds, ribbons, or capsules, which are placed in the body or near the cancer cells. Used for cancers of the head, neck, breast, uterus, cervix, prostate, gall bladder, oesophagus, eye, and lung. Internal radiation can also be in a liquid form used with people who have thyroid cancer or non-Hodgkin's lymphoma.

Chemotherapy

Chemotherapy is usually given as an intravenous injection or drip, but sometimes drugs are in the form of a tablet. A list of chemotherapeutic drugs is given in Appendix 3.

Hormonal therapy

Hormonal therapy medicines are whole-body (systemic) treatment for hormone-receptor-positive cancers, such as some breast and prostate cancers. They include:

Hormonal Agent	Brand Name(S)	Hormonal Agent	Brand Name(S)
Anastrozole	Arimidex	Goserelin (Breast)	Zoladex
Abiraterone acetate	Zytiga	Goserelin (Prostate)	Zoladex, Zoladex LA, Novgos
Bicalutamide	Casodex	Letrozole	Femara
Buserelin	Suprefact	Leuprorelin acetate	Prostap SR, Prostap 3
Cyproterone	Cyprostat	Medroxyprogesterone	Provera
Degarelix	Firmagon	Megestrol acetate	Megace
Diethylstilbestrol	Stilboestrol	Tamoxifen	Nolvadex, Tamoxen, Tamosin, Tamofen
Exemestane	Aromasin	Toremifene	Fareston
Flutamide	Drogenil	Triptorelin	Decapeptyl SR, Gonapeptyl Depo
Fulvestrant	Faslodex		

Immunotherapy

Immunotherapy (also called biologic therapy or biotherapy) uses materials either made by the body or in a laboratory to improve, target, or restore immune system function. There are several types of immunotherapy, including non-specific immunotherapies (e.g. aldesleukin, interferon) and monoclonal antibodies.

Immunotherapy Agent	Brand Name(S)	Immunotherapy Agent	Brand Name(S)
Aldesleukin	Proleukin	Iodine-131 tositumomab	Bexxar
Interferon	IntronA, Roferon-A	Ipilimumab	Yervoy
90Y-Ibritumomab tiuxetan	Zevalin	Panitumumab	Vectibix
Bevacizumab	Avastin	Rituximab	Mabthera
Cetuximab	Erbitux	Trastuzumab	Herceptin
Gemtuzumab	Mylotarg		

4.4.5 SOURCE OF INFORMATION

It is important to record the source of information every time a cancer case is identified from one of the sources. The source may be a hospital, clinic, hospice, laboratory, or a death certificate.

Clearly write the details of the source (ward or service of a hospital, which laboratory etc.) so that it can be coded.

Record the patient's FILE NUMBER as provided on the cover of the medical records file or the laboratory reference number (e.g. Pathology number) from the report.

For each source, record the DATE:

- ☞ For hospital cases, the date of admission to the hospital
- ☞ For out-patients – the date of consultation
- ☞ For laboratories, the date of examination (as given in the laboratory/ X-Ray report).

This is very important – these numbers will be needed if the case record is needed to be traced using the cancer registry database.

4.4.6 FOLLOW UP

It is important to have follow-up information of each cancer patient registered.

Follow-up information is important when estimating cancer survival as a measure of outcome. Information expected is either the patient is alive or dead or unknown (lost to follow-up). Follow-up procedures employed by the registry should be clearly specified.

- Active follow up may be done for special studies - by contacting the patient's physician or the patients themselves (by telephone, mail, or home visits).
- Access to death register/death certificates allows them to be used as a passive method of follow up.

Date of last contact

Refers to the latest date for which there is ANY information about the patient. It may be:

- The date he/she was last known to be alive
- The date of death

At the time of the first registration, this will probably be the date of discharge from hospital (or of outpatient appointment).

More information (later dates) may come from follow-up visits to the same hospital, or from admission elsewhere (e.g. radiotherapy or hospice care).

For death certificate registrations, Date of Last Contact = Date of Death.

Give date of last contact as the complete date, including day, month and year.

Status at last contact

Record whether the patient was alive or dead on the Date of Last Contact.
Codes: 1 Alive 2 Dead

Try **NOT** to code 9 ("Unknown") – the status of the patient on the date of last follow up should never be "unknown" when information on them was traced!

Cause of death

If the patient was alive on date of last contact, enter "Not applicable" (Code = 8) in CanReg.

If the patient was dead, there are two options for recording the cause of death:

- 1 Dead of cancer 2 Dead of other cause 9 Not known.

OR

- The underlying cause of death as specified in the death certificate.

Where is the "underlying cause of death"? If the death certificate uses the WHO recommended standard form of medical certification (Fig 4. 2, page 11):

In Part I, the cause leading directly to death is reported on line (**a**),
The intervening antecedent condition (if any) on line (**b**), and
The underlying cause of death on line (**c**).

If the entry on line (**a**), or on lines (**a**) and (**b**)**,** completely describe the sequence of events leading to death, then it is no longer necessary to put an entry on line (**c**).

Part II is for any condition which may contribute to death but is not related to the disease or condition causing the death.

For coding the underlying cause of death, use the appropriate codes of the International Classification of Diseases (ICD-10).