
“CHAPTER I”
INTRODUCTION

THE NEED FOR DATA

Cancer has long been a major problem in the more developed countries, and is now a major public health problem in all countries. Cancer is not a single disease; it is a term that describes many different diseases. Therefore, it is not sufficient to know the total number of cancers in a population, because patterns of occurrence vary widely between geographical areas, between ethnic groups, by socio-economic categories, by occupation and by a wide variety of cultural factors. This is why data on cancer have to show the distribution of the different types of cancer in a population. It is the role of the Palau Cancer Registry to collect the data, which will give an accurate picture of cancer in the population, in order to understand and to control the impact of cancer in the population. Analysis of the data collected will show how many cancers there are, and which types are the most frequent. This will help permit studies to identify the causes of cancer, and at the same time the registry data can be used to evaluate the effect of screening programmes or other activities designed to reduce cancer incidence in the population, as well as to study the effect of early diagnosis and of treatment. The cancer registry data will also be used to plan requirements for the personnel, medical facilities and equipment needed for the diagnosis and treatment of the cancer patient.

THE MANUAL

This manual has been prepared to help people working in the Palau Cancer Registry, a population-based cancer registry. The different chapters should be able to give an overview of the tasks that have to be performed by the registry personnel beginning with the understanding of the U.S. Cancer Registry Amendment Act (Public Law 102-515) and the Palau Cancer Registry Act (RPPL No. 5-33), in Chapter II. Chapter III introduces the registry personnel to the different organizations that the Registry is associated with. Chapter IV is the actual tasks, which has to be performed by the registry personnel, beginning with how to recognize the medical vocabulary used to describe the symptoms, the diagnosis and the treatment of cancer and ending with ensuring data confidentiality.

The design of this manual is for anybody new to the registry and not necessary a person with medical training. Anyone who may have medical training or background may not necessarily need to study the medical terminology section of this manual. It is designed to help a person understand the basics to human physiology and the terms they may come across in medical records. The registry personnel when necessary can add additional changes and additions to this manual.

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“CHAPTER II”
THE US CANCER REGISTRY AMMENDMENT ACT
Public Law 102-515
October 24, 1992

An Act

Entitled the “Cancer Registries Amendment Act”.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Cancer Registries Amendment Act”.

SEC. 2. FINDINGS AND PURPOSE.

(a) FINDINGS.—Congress finds that—

(1) cancer control efforts, including prevention and early detection, are best addressed locally by State health departments that can identify unique needs;

(2) cancer control programs and existing statewide population-based cancer registries have identified cancer incidence and cancer mortality rates that indicate the burden of cancer for Americans is substantial and varies widely by geographic location and by ethnicity;

(3) statewide cancer incidence and cancer mortality data, can be used to identify cancer trends, patterns, and variation for directing cancer control intervention;

(4) the American Association of Central Cancer Registries (AACCR) cites that of the 50 States, approximately 38 have established cancer registries, many are not statewide and 10 have no cancer registry; and

(5) AACCR also cites that of the 50 States, 39 collect data on less than 100 percent of their population, and less than half have adequate resources for insuring minimum standards for quality and for completeness of case information.

(b) PURPOSE.—It is the purpose of this Act to establish a national program of cancer registries.

SEC. 3. NATIONAL PROGRAM OF CANCER REGISTRIES.

Title III of the Public Health Service Act (42 U.S.C. 241 et seq.) is amended by adding at the end the following new part:

“PART M—NATIONAL PROGRAM OF CANCER REGISTRIES

“SEC. 399H. NATIONAL PROGRAM OF CANCER REGISTRIES.

“(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control, may make grants to States, or may make grants or enter into contracts with academic or nonprofit organizations designated by the State to operate the State’s cancer registry in lieu of making a grant directly to the State, to support the operation of population-based, statewide cancer registries in order to collect, for each form of in-situ and invasive cancer (with the exception of basal cell and squamous cell carcinoma of the skin), data concerning—

“(1) demographic information about each case of cancer;

“(2) information on the industrial or occupational history of the individuals with the cancers, to the extent such information is available from the same record;

“(3) administrative information, including date of diagnosis and source of information;

“(4) pathological data characterizing the cancer, including the cancer site, stage of disease (pursuant to Staging Guide), incidence, and type of treatment; and

“(5) other elements determined appropriate by the Secretary.

“(b) MATCHING FUNDS.—

“(1) IN GENERAL.—The Secretary may make a grant under subsection (a) only if the State, or the academic or nonprofit private organization designated by the State to operate the cancer registry of the State, involved agrees, with respect to the costs of the program, to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs or \$1 for every \$3 of Federal funds provided in the grant.

“(2) DETERMINATION OF AMOUNT OF NON-FEDERAL CONTRIBUTION; MAINTENANCE OF EFFORT.—

“(A) Non-Federal contributions required in paragraph (1) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the amount of such non-Federal contributions.

“(B) With respect to a State in which the purpose described in subsection (a) is to be carried out, the Secretary, in making a determination of the amount of non-Federal contributions provided under paragraph (1), may include only such contributions as are in excess of the amount of such contributions made by the State toward the collection of data on cancer for the fiscal year preceding the first year for which a grant under subsection (a) is made with respect to the State. The Secretary may decrease the amount of non-Federal contributions that otherwise would have been required by this subsection in those cases in which the State can demonstrate that decreasing such amount is appropriate because of financial hardship.

“(c) ELIGIBILITY FOR GRANTS.—

“(1) IN GENERAL.—No grant shall be made by the Secretary under subsection (a) unless an application has been submitted to, and approved by, the Secretary. Such application shall be in such form, submitted in such a manner, and be accompanied by such information, as the Secretary may specify. No such application may be approved unless it contains assurances that the applicant will use the funds provided only for the purposes specified in the approved application and in accordance with the requirements of this section, that the application will establish such fiscal control and fund accounting procedures as may be necessary to assure proper disbursement and accounting of Federal funds paid to the applicant under subsection (a) of this section, and that the applicant will comply with the peer review requirements under sections 491 and 492.

“(2) ASSURANCES.—Each applicant, prior to receiving Federal funds under subsection (a), shall provide assurances satisfactory to the Secretary that the applicant will—

“(A) provide for the establishment of a registry in accordance with subsection (a);

“(B) comply with appropriate standards of completeness, timeliness, and quality of population-based cancer registry data;

“(C) provide for the annual publication of reports of cancer data under subsection (a); and

“(D) provide for the authorization under State law of the statewide cancer registry, including promulgation of regulations providing—

“(i) a means to assure complete reporting of cancer cases (as described in subsection (a)) to the statewide cancer registry by hospitals or other facilities providing screening, diagnostic or therapeutic services to patients with respect to cancer;

“(ii) a means to assure the complete reporting of cancer cases (as defined in subsection (a)) to the statewide cancer registry by physicians, surgeons, and all other health care practitioners diagnosing or providing treatment for cancer patients, except for cases directly referred to or previously admitted to a hospital or other facility providing screening, diagnostic or therapeutic services to patients in that State and reported by those facilities;

“(iii) a means for the statewide cancer registry to access all records of physicians and surgeons, hospitals, outpatient clinics, nursing homes, and all other facilities, individuals, or agencies providing such services to patients which would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified patient;

“(iv) for the reporting of cancer case data to the statewide cancer registry in such a format, with such data elements, and in accordance with such standards of quality timeliness and completeness, as may be established by the Secretary;

“(v) for the protection of the confidentiality of all cancer case data reported to the statewide cancer registry, including a prohibition on disclosure to any person of information reported to the statewide cancer registry that identifies, or could lead to the identification of, an individual cancer patient, except for disclosure to other State cancer registries and local and State health officers;

“(vi) for a means by which confidential case data may in accordance with State law be disclosed to cancer researchers for the purposes of cancer prevention, control and research;

“(vii) for the authorization or the conduct, by the statewide cancer registry or other persons and organizations, of studies utilizing statewide cancer registry data, including studies of the sources and causes of cancer, evaluations of the cost, quality, efficacy, and appropriateness of diagnostic, therapeutic, rehabilitative, and preventative services and programs relating to cancer, and any other clinical, epidemiological, or other cancer research; and

“(viii) for protection for individuals complying with the law, including provisions specifying that no person shall be held liable in any civil action with respect to a cancer case report provided to the statewide cancer registry, or with respect to access to cancer case information provided to the statewide cancer registry.

“(d) RELATIONSHIP TO CERTAIN PROGRAMS.—

“(1) IN GENERAL.—This section may not be construed to act as a replacement for or diminishment of the program carried out by the Director of the National Cancer Institute and designated by such Director as the Surveillance, Epidemiology, and End Results Program (SEER).

“(2) SUPPLANTING OF ACTIVITIES.—In areas where both such programs exist, the Secretary shall ensure that SEER support is not supplanted and that any additional activities are consistent with the

guidelines provided for in subsection (c)(2) (C) and (D) and are appropriately coordinated with the existing SEER program.

“(3) TRANSFER OF RESPONSIBILITY.—The Secretary may not transfer administration responsibility for such SEER program from such Director.

“(4) COORDINATION.—To encourage the greatest possible efficiency and effectiveness of Federally supported efforts with respect to the activities described in this subsection, the Secretary shall take steps to assure the appropriate coordination of programs supported under this part with existing Federally supported cancer registry programs.

“(e) REQUIREMENT REGARDING CERTAIN STUDY ON BREAST

CANCER.—In the case of a grant under subsection (a) to any State specified in section 399K(b), the Secretary may establish such conditions regarding the receipt of the grant as the Secretary determines are necessary to facilitate the collection of data for the study carried out under section 399C.

“SEC. 399I. PLANNING GRANTS REGARDING REGISTRIES.

“(a) IN GENERAL.—

“(1) STATES.—The Secretary, acting through the Director of the Centers for Disease Control, may make grants to States for the purpose of developing plans that meet the assurances required by the Secretary under section 399B(c)(2).

“(2) OTHER ENTITIES.—For the purpose described in paragraph (1), the Secretary may make grants to public entities other than States and to nonprofit private entities. Such a grant may be made to an entity only if the State in which the purpose is to be carried out has certified that the State approves the entity as qualified to carry out the purpose.

“(b) APPLICATION.—The Secretary may make a grant under subsection (a) only if an application for the grant is submitted to the Secretary, the application contains the certification required in subsection (a)(2) (if the application is for a grant under such subsection-42) and the application in such form, is made in such manner, and contains such agreements, assurances, and information as the Secretary determines to be necessary to carry out this section.

“SEC. 399J. TECHNICAL ASSISTANCE IN OPERATIONS OF STATEWIDE CANCER REGISTRIES.

“The Secretary, acting through the Director of the Centers for Disease Control, may, directly or through grants and contracts, or both, provide technical assistance to the States in the establishment and operation of statewide registries, including assistance in the development of model legislation for statewide cancer registries and assistance in establishing a computerized reporting and data processing system.

“SEC. 399K. STUDY IN CERTAIN STATES TO DETERMINE THE FACTORS CONTRIBUTING TO THE ELEVATED BREAST CANCER MORTALITY RATES.

“(a) IN GENERAL.—Subject to subsections (c) and (d), the Secretary, acting through the Director of the National Cancer Institute, shall conduct a study for the purpose of determining the factors contributing to the fact that breast cancer mortality rates in the States specified in subsection (b) are elevated compared to rates in other States.

“(b) RELEVANT STATES.—The States referred to in subsection (a) are Connecticut, Delaware, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Rhode Island, Vermont, and the District of Columbia.

“(c) COOPERATION OF STATE.—The Secretary may conduct the study required in subsection (a) in a State only if the State agrees to cooperate with the Secretary in the conduct of the study, including providing information from any registry operated by the State pursuant to section 399H(a).

“(d) PLANNING, COMMENCEMENT, AND DURATION.—The Secretary shall, during each of the fiscal years 1993 and 1994, develop a plan for conducting the study required in subsection (a). The study shall be initiated by the Secretary not later than fiscal year 1994, and the collection of data under the study may continue through fiscal year 1998.

“(e) REPORT.—Not later than September 30, 1999, the Secretary shall complete the study required in subsection (a) and submit to the Committee on Energy and Commerce of the House of Representatives, and to the Committee on Labor and Human Resources of the Senate, a report describing the findings and recommendations made as a result of the study.

“SEC. 399L. AUTHORIZATION OF APPROPRIATIONS.

“(a) REGISTRIES.—For the purpose of carrying out this part, the Secretary may use \$30,000,000 for each of the fiscal years 1993 through 1997. Out of any amounts used for any such fiscal year, the Secretary may obligate not more than 25 percent for carrying out section 399I, and not more than 10 percent may be expended for assessing the accuracy, completeness and quality of data collected, and not more than 10 percent of which is to be expended under subsection 399J.

“(b) BREAST CANCER STUDY.—Of the amounts appropriated for the National Cancer Institute under subpart 1 of part C of title IV for any fiscal year in which the study required in section 399K is being carried out, the Secretary shall expend not less than \$1,000,000 for the study.”

Approved October 24, 1992.

PALAU CANCER REGISTRY ACT

On August 4, 1999, RPPL No. 5-33 was signed by President Kuniwo Nakamura to “establish a cancer registry system for the collection of information on the incidence of cancer and related data; to provide for the confidentiality of identifying information regarding individual patients, health care facilities and health care providers; and for related purposes.”

The RPPL 5-33 is also known as “Cancer Registry Act”

Section 1. “Short title.” This Act may be cited as the “Cancer Registry Act.”

Section 2. “Definitions.” As used in this Act

- (a) “Cancer.” means all malignant neoplasms, regardless of the tissue of origin, including malignant lymphoma disease.
- (b) “Health care facility.” means hospital, nursing home or other institution that provides medical care in the Republic of Palau.
- (c) “Health care provider.” means a physician (M.D., M.B.B.S., M.O., D.O., D.D.S), medex, nurse practitioner, registered nurse, nurse midwife, practical nurse or health assistant licensed in the Republic of Palau.
- (d) “Minister.” means the Minister of Health or person designated by the Minister to compile information, prepare reports, and performs any functions required or permitted under this act.

Section 3. Cancer Registry

- (a) The Minister of Health and each health care facility and health care providers shall jointly establish a uniform, nation-wide population-based cancer registry system for the collection of information regarding the incidence of cancer and related data. The Minister and each health care facility and health care providers shall jointly adopt rules necessary to effect the purposes of this Act, including the data to be reported and the effective date after which reporting by health care facilities and health care providers shall be required.
- (b) All cancers diagnosed or treated in the Republic shall be reported to the Minister to compile cancer related data.
- (c) The Minister shall establish a training program for the personnel of participating health care facilities and a quality control program for cancer data. The Minister shall collaborate in studies with clinicians and epidemiologists and publish reports on the results of studies. The Minister shall cooperate with the U.S. National Institutes of Health and the Center for Disease Control in providing cancer incidence data.

Section 4. Participation in Program

Each health care facility and health care provider diagnosing or providing treatment to cancer patients shall report to the Minister each cancer case that occurs within the facility or provider’s office. Within 120 days of the effective date of this Act, the Minister and each health care provider and health care facility shall jointly promulgate a plan to set forth the format, content, and timing of the report required by this section, including remedies and penalties for noncompliance. Any cancer patient whose diagnosis or treatment is reported to the Minister shall be informed of this fact by the

health care facility or health care provider prior to submission of the report. This section shall only apply to cancer cases diagnosed or treated following the effective date of this Act.

Section 5. Confidentiality

- (a) All information reported pursuant to this Act shall be confidential and privileged. The Minister shall take strict measures to ensure that all identifying information is kept confidential.
- (b) All identifying information regarding an individual patient, health care provider or health care facility contained in records of interviews, written reports and statements procured by the Minister, or by any other person, agency or organization acting jointly with the Minister, in connection with cancer morbidity and mortality studies shall be confidential and privileged and may be used solely for the purpose of the study. Nothing in this section shall prevent the Minister from publishing statistical compilation relating to morbidity and mortality studies, which do not identify individual cases or source of information.

Section 6. Disclosure

- (a) The Minister may enter into agreements to exchange confidential information with other cancer registries in order to obtain complete reports of Palau residents diagnosed or treated in other countries, subdivisions thereof, and to provide information to other countries, and subdivision thereof, regarding their residents diagnosed or treated in the Republic of Palau.
- (b) The Minister may furnish statistical information to other nation's cancer registries, cancer control agencies, or health researchers in order to collaborate in a national cancer registry or to collaborate in cancer control and prevention research studies. Before releasing confidential information, the Minister shall first obtain from such national registry, agency or researcher, a written agreement to keep the identifying information confidential and privileged. In the case of researchers, the Minister shall first *obtain evidence of the approval of his or her academic committee for the protection of human subjects or the equivalent.*

Section 7. Liability

- (a) *No action for damages arising from the disclosure of confidential or privileged information may be maintained against any person, or the employer or employee of any person, who participates in good faith in the reporting of cancer registry data or data for cancer morbidity or mortality studies in accordance with this Act.*
- (b) *No license of a health care facility or health care provider may be denied, suspended or revoked for the good faith disclosure of confidential or privileged information in the reporting of cancer registry data for cancer morbidity or mortality studies in accordance with this Act.*
- (c) *Nothing in this section shall be construed to apply to the unauthorized disclosure of confidential or privileged information when such disclosure is due to gross negligence or willful misconduct.*

Section 8. This Act shall take effect upon its approval by the President, or upon its becoming law without such approval, except as otherwise provide by law.

Approved on the 4th day of August 1999.

CHAPTER III
ASSOCIATIONS**CENTER FOR DISEASE CONTROL (CDC)**

The Centers for Disease Control and Prevention (CDC) is recognized as the lead federal agency for protecting the health and safety of people - at home and abroad, providing credible information to enhance health decisions, and promoting health through strong partnerships. CDC serves as the national focus for developing and applying disease prevention and control, environmental health, and health promotion and education activities designed to improve the health of the people of the United States.

The formal mission of CDC is:

To promote health and quality of life by preventing and controlling disease, injury, and disability.

Through the Congressional mandate Public Law (1998 Code), authorizes the Centers for Disease Control and Prevention (CDC) to provide funds to states and territories

- to improve existing cancer registries
- to plan and implement registries where they do not exist
- to develop model legislation and regulations for states to enhance the viability of registry operations
- to set standards for data completeness, timeliness, and quality
- to provide training for registry personnel, and
- to help establish a computerized reporting and data-processing system.

CDC and NCI have signed a Memorandum of Understanding to formalize collaboration between NCI's SEER and CDC's NPCR. This will allow a more coordinated national cancer surveillance effort that builds upon and strengthens the existing infrastructure, improves the availability of high quality data for measuring the nation's cancer burden, and advances the capacity for surveillance research.

CDC and NCI also collaborate by working together on various committees of the NAACCR. NAACCR is a collaborative umbrella organization for cancer registries, governmental agencies, professional associations, and private groups in North America interested in improving the quality and use of cancer registry data. NAACCR provides forums through its committees for discussion and consensus

THE NATIONAL PROGRAM OF CANCER REGISTRIES (NPCR)

US Congress established the National Program of Cancer Registries (NPCR) in 1992 by enacting the Cancer Registries Amendment Act, [Public Law 102-515](#). A Congressional mandate that reauthorized the National Program of Cancer Registries PUBLIC LAW (1998 CODE).

Before NPCR was established, 10 states had no registry and most states with registries lacked the resources and legislative support needed to gather complete data. With fiscal year 2002 funding of approximately \$40 million, CDC's NPCR supported central registries and promoted the use of registry data in 45 states, the District of Columbia, and the territories of Puerto Rico, **the Republic of Palau**, and the Virgin Islands. CDC also developed special research projects such as studies to examine patterns of cancer care in specific

populations. CDC's goal is for all states to maintain registries that provide high-quality data on cancer and cancer care.

NPCR complements NCI's Surveillance, Epidemiology, and End Results (SEER) registry program. Together, NPCR and the SEER program collect cancer data for the entire U.S. population. The SEER program gathers in-depth data on cancer cases diagnosed in Connecticut, Hawaii, Iowa, New Mexico, and Utah, as well as in six metropolitan areas and several rural/special population areas. The six metropolitan SEER registries and some of the rural/special population registries submit data to NPCR's state registries. In 2001, SEER began providing additional support to four NPCR-supported state registries (California, Kentucky, Louisiana, and New Jersey).

SURVEILLANCE, EPIDEMIOLOGY, AND END RESULTS (SEER)

The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute is an authoritative source of information on cancer incidence and survival in the United States. SEER began collecting data on cases on January 1, 1973, in the states of Connecticut, Iowa, New Mexico, Utah, and Hawaii and the metropolitan areas of Detroit and San Francisco-Oakland. In 1974-1975, the metropolitan area of Atlanta and the 13-county Seattle-Puget Sound area were added. In 1978, 10 predominantly black rural counties in Georgia were added, followed in 1980 by the addition of American Indians residing in Arizona. Three additional geographic areas participated in the SEER program prior to 1990: New Orleans, Louisiana (1974-1977, rejoined 2001); New Jersey (1979-1989, rejoined 2001); and Puerto Rico (1973-1989). The National Cancer Institute also funds a cancer registry that, with technical assistance from SEER, collects information on cancer cases among Alaska Native populations residing in Alaska. In 1992, the SEER Program was expanded to increase coverage of minority populations, especially Hispanics, by adding Los Angeles County and four counties in the San Jose-Monterey area south of San Francisco. In 2001, the SEER Program expanded coverage to include Kentucky and Greater California; in addition, New Jersey and Louisiana once again became participants.

The SEER Program currently collects and publishes cancer incidence and survival data from 14 population-based cancer registries and three supplemental registries covering approximately 26 percent of the US population. Information on more than 3 million in situ and invasive cancer cases is included in the SEER database, and approximately 170,000 new cases are added each year within the SEER coverage areas. The SEER Registries routinely collect data on patient demographics, primary tumor site, morphology, stage at diagnosis, first course of treatment, and follow-up for vital status. The SEER Program is the only comprehensive source of population-based information in the United States that includes stage of cancer at the time of diagnosis and survival rates within each stage. The mortality data reported by SEER are provided by the National Center for Health Statistics.

NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES (NAACCR)

Established in 1987, NAACCR, Inc. is a collaborative umbrella organization for cancer registries, governmental agencies, professional associations, and private groups in North America interested in enhancing the quality and use of cancer registry data. All central cancer registries in the United States and Canada are members. **Palau is an active member of the North American Association of Central Cancer Registries (NAACCR).**

The formal mission of NAACCR, Inc. is:

The North American Association of Central Cancer Registries, Inc. (NAACCR, Inc.), is a professional organization that develops and promotes uniform data standards for cancer registration; provides education and training; certifies population-based registries; aggregates and publishes data from central cancer registries; and promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care to reduce the burden of cancer in North America.

CHAPTER IV

PALAU CANCER REGISTRY PROTOCOL

The Diagnosis & Treatment

(This section is adopted by the IACR Manual for Cancer Registry Personnel by D. Esteban, S. Whelan, A. Laudico & D.M. Parkin)

In the day-to-day operations of the registry, the cancer registry personnel deal mostly with cases of cancer. They will encounter various terms that refer to symptoms or signs of the illness, describe the tumor and refer to the site of origin, as well as the methods and results of diagnosis and treatment. Worker should be able to decide whether these terms relate to the diagnosis or treatment of cancer, or whether they are used to describe the site or type of tumor. This section provides general information on symptoms of cancer, methods of detection and forms of treatment. Common medical terms are presented and defined.

Word Roots, Suffixes and Prefixes

Following terms do not have to be memorized by the registry workers. However, it is important that they learn the meaning of the more common word roots (or origins), prefixes (beginnings) and suffixes (endings) the parts of words which are combined to make up medical terms) to help in understanding difficult terms. Most medical terms are derived from languages such as Latin, Greek, French or German. As an example, the word arthralgia, which is based on the Greek word arthron (joint) as a root, and the suffix (ending)-algia, which is derived from the Greek, word algo (pain). Thus arthralgia means pain in the joint.

The root, also known as stem, of a medical term is usually the main part of the word and refers to the organ or place where the illness originated. It is generally derived from a Greek or Latin noun or verb. The root may be found:

- at the beginning , as in: osteoma, lingual, leukaemia
- in the middle: intercostals, hyperchromatic, prognosis
- at the end: anuria, neoplasm, hypogastric, mesoderm

The meaning of a medical term is modified by the addition of a prefix (at the beginning) or a suffix (at the end). The prefix is often a preposition or an adverb and it consists of one or two syllables added in front of the root of the word which alters its meaning. Examples are given below:

<i>Medical term</i>	<i>Prefix</i>	<i>Definitions of prefix</i>
Submandibular	Sub-	below
Hypogastric	Hypo-	beneath, under, deficient
Aphonia	a-	without
Anencephalic	An-	without
Endocardium	Endo-	inside
Bilateral	Bi-	two
Contralateral	Contra-	against, opposite

A suffix refers to a syllable or groups of syllables attached to the end of the root to modify its meaning. Suffixes, as prefixes, modify the meaning of a root element. Examples are:

<i>Medical term</i>	<i>Suffix</i>	<i>Definition of suffix</i>
Appendicitis	-itis	inflammation
Histology	-ology	study of
Leukopenia	-penia	deficiency
Carcinoid	-oid	form, resembling
Ovoid	-oid	form, like, resembling
Hepatomegaly	-megaly	enlargement
Hepatic	-ic	Condition of
Erythrocytosis	-osis	Abnormal increase, disease morbid status
Nephropathy	-pathy	Morbid condition (non-inflammatory)

Often, a root will be combined with a suffix and put after another root, so forming the word ending, for example:

- Leukaemia-Root (aem = blood) + suffix (-ia = condition), added to another root (leuk- = white), to form the word leukaemia.
- Carcinogenic – Genic is composed of a root (gen = forming, producing) + a suffix (-ic = condition of).

In summary, the basic forms of medical terms are:

Root plus suffix:

- Hepatoma: (heap = liver) + (-oma = tumour).
- Leukorrhea: (leuko = white) + (-rrhea = flow).

Prefix plus root:

- Neoplasm: (neo- = new) + (plasm = fluid substance of cells)
- Biology: (bio- = life, living) + (logy = study of)
- Pathology: (patho- = relating to disease) + (logy = study of)

Prefix plus root plus suffix:

- Epigastric: (epi- = on or upon) + (gastr = stomach) = (-ic = condition of), relates to the epigastrium at the upper middle region of the abdomen.
- Dyspneic: (dys- = difficult) + (pne = breathing) + (-ic = condition of) describes difficulty in breathing.
- Tachycardic: (tachy- = rapid) + (card = heart) + (-ic = condition of), describes rapid heart rate.

Two roots:

- Carcinogen: (carcin(o) = cancer, crab) + (gen = forming).
- Scleroderma: (sclera(o) = hard) + (derma = skin)*The vowel is in brackets because it has been introduced to combine the two root words.*

Tumor Formation and Pathology

The human body is composed of millions of microscopic units called cells. These are of different types and are arranged in different ways. A typical cell is enclosed in a cell membrane and contains a nucleus and cytoplasm. Groups of cells performing the same function form tissues. The epithelial tissue or epithelium lines the body cavities and provide protection and lubrication; connective tissue supports and holds other tissues together; muscle tissue is for movement and nervous tissue carries messages between the brain and spinal cord and the rest of the body. Several tissues operating together form organs, such as the heart, lungs liver, stomach, colon and kidneys. Different organs work together in a unit called an organ system each of which has a particular function in sustaining life.

Since the cell is the basic structural unit of the human body, any abnormality in the cell can result in abnormalities being carried through-out the tissues , organs and organ systems and may ultimately result in the malfunction of any or all of these. Tumour formation begins at the cellular level. Most cells are able to reproduce themselves in order to grow and to replace worn-out or injured cells: the exception is the cells of the brain. Tissues normally grow by increasing the number of cells through a process of cell division or mitosis.

The process of tissue growth is normally controlled by the body. In some persons, however, this normal life process gets out of control and the cells proliferate rapidly and uncontrollably, in a haphazard way, forming a 'neoplasm' 'new growth' or 'tumor' which serves no useful purpose for the body. The term 'tumor' and 'neoplasm' are often used inter-changeably. There are two general types of tumors or neoplasm's: benign (non-cancerous) and malignant (cancerous) tumors.

Symptoms

Among cancer patients, the presenting signs and symptoms vary with the different organs involved. The most pressing complaints which prompted the patient to seek medical attention are always recorded on a patient's record. To facilitate abstracting of the medical record, the Registry personnel should learn some medical terms describing symptomatology. In the list below are some symptoms, which may be indicative of malignancy.

1. *Unusual bleeding*-This may occur in the digestive tract, respiratory system, genitourinary tract or elsewhere. In the digestive or alimentary tract, unusual bleeding may occur as: Haematemesis: (haema- = blood) + (emesis = to vomit) = vomiting of blood. Melena: derived from the Greek word "melas", a root meaning black; this is defined as the passage of black, tarry stools, one of the signs of bleeding from the upper alimentary tract. In the respiratory system, bleeding may occur as: Epistaxis: (epi- = upon, over, in addition) + (staxis = haemorrhage) from the nose or Haemoptysis: (haemo- = blood) + (pty + saliva) + (-sis = condition of), a condition characterized by spitting up or coughing up of blood. In the genitor-urinary tract, unusual bleeding may occur as: Haematuria: (haemat- = blood) + (ur = urine) + (-ia = condition of) = a condition characterized by blood in the urine. Menorrhagia: (meno = menstruation) + (-rrhagia = excessive flow), an excessive menstrual flow. Metrorrhagia: (metro = uterus) + (-rrhagia = excessive flow) = uterine bleeding. Unusual bleeding may also occur in the form of haematoma, haematoperitoneum, and haemothorax.
2. *Unusual discharge*-The suffix used to indicate discharge is "-rrhea". This is attached to different words roots to indicate the site where this occurs, or the type of discharge. Galactorrhea: (galact(o) = milk) = (-rrhea = flow, discharge), an excessive or spontaneous milk flow. Rhinorrhea: (rhino = nose) + (-rrhea = flow, discharge), a watery nasal discharge. Bronchorrhea: (broncho = windpipe) = (-rrhea = flow, discharge), a discharge of mucus from the bronchi. Leukorrhea: (leuko = white) + (-rrhea = flow, discharge), the white discharge from vagina or the uterine cavity.
3. *Changes in bowel habits*-This usually indicates disease in the gastrointestinal tract, particularly the colon and rectum, and may occur in the form of: Diarrhea: (dia = across, through) + (-rrhea = flow, discharge), abnormal frequency and loose-ness of bowel movements. Constipation: infrequent or difficult evacuation of faeces.
4. *Change in urinary habits*-This usually indicates disease in the genito-urinary system. It may occur in the form of: Dysuria: (dys- = difficult, painful) + (ur = urine) + (-ia = condition of), a condition characterized by painful or difficult urination. Polyuria: (poly- = many) + (ur = urine) + (-ia = condition of), an excessive secretion of urine or increased frequency in urination. Another term for this is 'frequent urination'. Urgency: a compelling desire to urinate. Oliguria: (olig- = scant) + (ur = urine) + (-ia = condition of), a condition characterized by diminished urine secretion. Anuria: (an- = without) + (ur = urine) + (-ia = condition of), a condition characterized by no urine formation. Nocturia: (noct- = night) + (ur = urine) + (-ia = condition of), increased frequency of urination during the night.

5. *Indigestion or difficulty in swallowing*-This may indicate disease in the upper digestive tract, and may occur in the form of: Dysphagia: (dys- = difficult, pain-ful) + (phag = eat) + (-ia = condition of), difficulty or pain in swallowing. Nausea: a sensation referred to the epigastrium or abdomen, with tendency to vomit. Vomiting or emesis: the forcible ejection of contents of the stomach through the mouth ('throwing up'). Hyperemesis: (hyper- = excessive) + (emesis = vomiting), intractable or excessive vomiting. Dyspepsia: (dys- = difficult) + (peps = digest) + (-ia = condition of), epigastric discomfort after meals, more commonly referred to as 'wind' or 'indigestion'. Anorexia: (an- = without) + (orexia = appetite), lack of appetite.
6. *Cough or hoarseness of voice*- This may indicate disease in the larynx or the respiratory system. A change in voice or difficulty in speaking is a condition also termed dysphonia: (dys- = difficult) + (phon = sound) + (-ia = condition of). Aponia: (a- = without) + (phon = sound) + (-ia = condition of), the inability to produce vocal sounds. Dyspnea: (dys- = difficult) + (pne = breath) + (-a = condition of), a condition characterized by difficulty in breathing. Orthopnea: (ortho- = upright) + (pne = breath) + (-a = condition of), a condition characterized by difficulty in breathing except in the upright position. Tachypnea: (tachy- = rapid) + (pne = breath) + (-a = condition of), very rapid respiration. Apnea: (a- = absent) + (pne = breath) + (-a = condition of), cessation of breathing.
7. *Change in a mole or wart*-Moles or warts, which increase in size rapidly or change in color or become ulcerated or bleed, may be evolving into skin cancer.
8. *A sore that does not heal*-In the skin or mucosa, this may be a sign of malignancy.
9. *A mass, lump or thickening*-In the breast or elsewhere, this may be a tumor beginning in that organ or it may be a metastatic focus from another organ. The patient may complain of abdominal enlargement, which may be due to enlargement of organs such as the liver, spleen, kidney, ovaries or other organs.
10. *Unexplained anaemia*-Anaemia: (a- = without) + (aem = will be recorded in the patient's medical blood) + (-ia = condition of) is a deficiency in the number of the red blood cells or the quantity of haemoglobin in the blood, which may result from decreased formation of red blood cells, or increased destruction of these cells, or bleeding. Patients with anemia complain of pallor or paleness of the skin. They also complain of dizziness, fainting spells fatigue and breathlessness. The formation or production of red blood cells or erythrocytes: (erythro- = red) + (cytes = cells), is known as erythropoiesis: (erythro- = red) + (poie = make, produce) + (-sis = condition of). The destruction of red blood cells can result from the process of haemolysis being more marked than is usual.
11. *Unexplained loss of weight*- Cancer is often associated with loss of weight. This has been attributed to the effects of the tumor itself resulting in decreased nutrient intake. Prolonged periods of malnutrition may result in a generalized physical wasting of the body known as cachexia. Hence, in the absence of other symptoms, a patient with unexplained weight loss may be suspected of having cancer. Occasionally cancer may be diagnosed in patients who have no complaints (asymptomatic) – for example, in patients who undergo routine physical examination or who participate in screening programmes.

Physical Signs

These are the findings of the doctor during physical examination. The physical findings begin with a general description of the patient's condition, for example, his nutritional status or development, whether he is able to walk (ambulatory) or is confined to bed. The physical examination often proceeds from the head, eyes, ears, nose, throat (HEENT), down to the neck, the breast, chest, lungs, heart, abdomen, genitalia, rectum, extremities, skin and lymph nodes as well as assessment of the musculo-skeletal system and the nervous system.

In the course of physical examination, the physician notes for example the presence of any masses or swelling; the presence of asymmetry (a dissimilarity in corresponding parts or organs on opposite sides of the body which are normally alike); the presence of sores or non-healing wounds; and abnormal discoloration of skin and mucous membranes; as well as impairment in motor (muscular function) or sensory functions (sensation).

In the list below are some of the physical findings which a tumor registrar may encounter while reviewing the medical records.

1. *Changes in the color of skin and mucous membranes*
 - a. Pallor: paleness of the skin or mucous membrane. This is noted in the presence of anemia especially following blood loss or hemorrhage: (haemo = blood) + (-rrhagia = excessive flow).
 - b. Icterus or jaundice: yellowish discoloration of skin and mucous membranes. This is seen in the presence of liver disease or those of the biliary tract, e.g., in blockage of the bile ducts that drain the bile from the liver to the intestine.
 - c. Cyanosis: bluish discoloration of the skin and mucous membrane due to the insufficient oxygen or high concentration of reduced hemoglobin in the blood. Cyanosis is derived from: (cyano = blue) + (-sis = condition of).
2. *Presence of non-healing wound or ulceration in the skin or mucosal lining of an organ-*
An ulceration in the skin or other organs of the body is often not due to malignancy. It may be inflammatory in nature or it may be due to impairment of circulation or poor nutrition. However, it can be secondary to a malignant process in the skin or to deeper organs with extension to the skin. The ulceration may be associated with a foul-smelling discharge, which may be purulent, sanguineous (bloody) or mixed (sanguine-purulent).
3. *Presence of masses-*Masses can occur in the skin, in the subcutaneous tissue, in the muscle, or in the bone or other organs of the body. Masses may be benign as in cysts or benign tumors; they can also be malignant. A small lump or thickening in the breast may be one of the early signs of breast cancer. A mass in neck, for example, may be a thyroid tumor or it may be an enlarged lymph node secondary to a primary nasopharyngeal malignancy or stomach cancer. A mass in abdomen may be due to enlarged organs such as the liver, the spleen, the ovaries, or uterus.
 - a. Hepatomegaly: (hepat- = liver_ + (megal = abnormal enlargement) + (-y = characterized by), enlargement of the liver.
 - b. Splenomegaly: (spleen- = abnormal enlargement) + (-y = characterized by), enlargement of the spleen.

The mass may be enlarged lymph nodes or groups of lymph nodes. This is also known as lymphadenopathy (lympho- referring to the lymphatic system) + (adeno = gland) + (-pathy = disease), disease of the lymph node. Lymph node enlargements due to cancer are usually secondary as in regional lymph node involvement or distant lymph node metastasis, with the primary site of the tumor occurring elsewhere (see section 2.1.2). Malignancy, however, may originate in lymph nodes, as in lymphomas like Hodgkin's disease and non-Hodgkin lymphoma. An abdominal mass may also be secondary to dilatation of the stomach or the colon, as a result of obstruction to the digestive tract. It

may also be due to a distended bladder. The physician may be able to indicate which is most likely.

4. *Accumulation of fluid in some portions of the body*

- a. Ascites: accumulation of fluid in the abdominal or peritoneal cavity. If the fluid in the peritoneal cavity is bloody, this is known as haemoperitoneum (peritoneum is the membrane lining the abdominal cavity).
- b. Pleural effusion: accumulation of fluid in the pleural cavity, also known as hydrothorax. If the fluid in the pleural cavity is bloody, this is known as haemothorax.
- c. Oedema: abnormal accumulation of fluid in connective tissue or serous cavity.

5. *Obstruction in the circulatory system*

- a. Venous obstruction: signs of venous obstruction include dilated or distended veins or swelling of the face or the extremities. For example, if there is an obstruction in the superior vena cava (the main vein returning blood from the upper body to the heart) this is manifested by dilated veins over the neck and chest associated with puffiness or oedema of the face and arms.
- b. Arterial obstruction-Obstruction of an arterial blood supply results in a diminished or absent blood supply from the heart to the tissues or cells supplied by the blocked artery. The affected cells die from lack of oxygen and food, resulting in a condition known as necrosis: derived from the Greek word root “necro-“ meaning death and the suffix “-sis” meaning a condition of. Necrosis refers to death or decay of cells or tissues in a part of the body.

6. *Assessment of motor function, the ability of the patient to move his/her limbs or other parts of the body-Paralysis: refers to the loss or impairment of motor function in a part of the body due to neural (nerve) or muscular mechanism. Another term for paralysis is palsy. Example: paralysis of one side of the face due to a lesion in the facial nerve is known as Bell’s palsy. The suffix “-plegia” is used to indicate paralysis as in: Hemiplegia: (hemi- = half) + (plegia = paralysis), paralysis of one half or one side of the body. Quadriplegia: (quadr(i)- = four) + (plegia = paralysis), paralysis of all four limbs. Paraplegia: (para- = beside, beyond) + (plegia = paralysis), paralysis of the lower part of the body, including the legs. Paresis: derived from the Greek word ‘paresis’, meaning relaxation, refers to slight or incomplete paralysis. Hemiparesis: (hemi- = half) + (paresis = incomplete paralysis), muscular weakness affecting one half of the body. Paraparesis: (para- = beside, beyond) + (paresis = incomplete paralysis), muscular weakness or partial paralysis of the lower extremities.*

7. *Assessment of sensory function or the ability of the patient to see, hear, smell, taste and feel (touch, pain, temperature). The word root “aesth(a)esi(o)”, which means feeling, is used as in: Anaesthesia: (an- = without) + (aesthesia = feeling) + (-ia = condition of), loss of feeling or sensation, especially to pain. Hypoaesthesia: (hyp- = deficient) + (aesthesia = feeling) + (-ia = condition of), decreased sensitivity to stimulation or decreased sensation. Hyperaesthesia: (hyper- = increased) + (aesthesia = feeling) + (-ia = condition of), increased sensitivity to stimulation or sensation. Paraesthesia: an abnormal sensation like tingling, burning or prickling. Dysaesthesia: an abnormal sensation resulting from a normal stimulus.*

Diagnostic Method

In order to arrive at a diagnosis, a physician employs several methods. In the cancer registry, these are grouped into several categories, and the registrar is expected to be able to decide which were used. A common grouping is:

- A. *Non-microscopic methods*
 - 1. Clinical only
 - 2. Clinical investigations
 - a. Laboratory examinations
 - b. Radiological examinations or x-rays
 - c. Ultrasound
 - d. Nuclear medicine
 - e. CT scan
 - f. Magnetic resonance imaging
 - g. Endoscopy
 - 3. Exploratory surgery/autopsy
 - 4. Specific biochemical and/ or immunological tests

- B. *Microscopic methods*
 - 5. Cytology or hematology
 - 6. Histology of metastasis
 - 7. Histology of primary tumor
 - 8. Autopsy

Non-Microscopic methods-Non-microscopic methods of diagnosis, as the name implies, do not confirm the diagnosis by examining cells or tissues under the microscope. Diagnosis is arrived at through the following methods:

- 1. *Clinical only*-The diagnosis is based on the clinical history and physical examination. Example: A fungating mass almost involving the whole breast, associated with enlarged lymph nodes in both auxiliary regions and at the supra-clavicular region may be diagnosed as breast cancer based on this method.

- 2. *Clinical investigations*-The diagnosis is based on clinical history and physical examination, with the aid of ancillary procedures such as laboratory examinations, diagnostic radiology, scan, ultrasound and other imaging techniques.
 - a. *Laboratory examinations*-These includes liver function tests, serum calcium, and other blood chemistries. T and B cell marker studies and chromosome studies may also fall under this category. Example: A clinical impression of breast cancer, with bone metastases, is supported by the finding of an abnormal or elevated alkaline phosphatase in a blood test.

 - b. *Diagnostic radiology*: Cancer is detected by means of X-rays. Example: A clinical impression of breast cancer with lung metastasis is supported by the finding of multiple nodular densities representing metastasis of the cancer in both lungs on a chest x-ray. An x-ray examination, however, may require the taking of several pictures, the results of which are summarized in one report.

Examples: A metastatic series, which involves taking x-rays of various parts of the body to determine whether or not cancer has spread to any of these parts. A skeletal survey, which involves taking a number of x-ray pictures of various parts of the body to rule out the presence of bone metastases.

There are different types of radiological examinations:

Body section radiography: this involves a series of x-ray taken at different depths in order to obtain defined images of specific areas. The image required is brought sharply into focus while the other areas are blurred out. These types of x-rays are used to locate lesions accurately in solid organs like the lungs and bones. They are also known as tomogram, laminograms or plano grams.

Radiological examinations using contrast media: a contrast medium is a radiopaque substance, which can be injected into the veins, arteries, lymphatic vessels or hollow cavities to obtain contrast with the surrounding tissues. The contrast medium does not permit X-rays to pass through it so that the structures containing it appear white on the X-ray film, thus delineating abnormal masses or growths and defining the contour of the body structures on X-ray. Some of the X-ray studies using contrast media are:

Angiography: (angio = vessel) + (-graphy = method of recording), the radiological study of the blood vessels (vascular system) or lymphatic vessels. Examples: cerebral angiogram: x-rays of the blood vessels of the brain. Cardiac angiogram: x-ray showing the blood vessels of the heart and the large blood vessels. Lymphangiogram: x-ray studies of the lymphatic vessels.

Bronchography: (broncho = windpipe) + (-graphy = method of recording), the radiological study of the airways (bronchi) of the lung. Bronchogram: x-ray of the bronchial system.

Cholecystography: (chole- = bile) + (cyst(0) = sac) + (-graphy = method of recording), the radiological study of the functions of the gallbladder and bile ducts after introduction of an opaque contrast medium. Cholecystogram: x-ray of the gallbladder.

Cholangiography: (chol(e)- = bile) + (angi(o) = vessel) + (-graphy = method of recording), the radiological study of the bile ducts. T-tube cholangiography: medium injected through a tube inserted during operation. Percutaneous transhepatic cholangiography (PTC): direct introduction of contrast medium through the liver into a bile duct usually carried out under television monitor. This procedure demonstrates the presence of obstruction either by a stone or by a mass as in a tumor.

Endoscopic retrograde cholangiopancreatography (ERCP): cannula into the opening of the bile duct, by using a flexible (fiberoptic duodenoscope). Contrast medium is introduced into the cannulated duct system and x-ray pictures are taken. As the cannula is withdrawn, more x-ray films are taken in various projections. *Operative cholangiography:* surgical procedure of the gallbladder.

Upper GI Series (UGIS or barium swallow): the patient is asked to take barium (a contrast medium) orally, than a series of x-ray pictures is taken as the barium goes down from the pharynx to the esophagus, stomach and small intestines.

Lower GI series (Barium Enema): radiological studies of the rectum and colon following introduction of barium through the rectum.

Myelography: (myel(o) = spinal cord) + (-graphy = method of recording), radiological study of the spinal cord.

Sialography: (sial(o) = salivary gland) + (-graphy = method of recording), radiological study of the salivary ducts.

Urography: (uro = urine, urinary tract) + (-graphy + method of recording), radiological study of the urinary tract.

Cystography: x-ray of the urinary bladder.

Pyelography: x-ray of the kidneys, ureter with emphasis on the pelvis of the kidney and ureters.

Intravenous pyelography (IVP): contrast medium is injected intravenously and a series of x-rays is taken as the contrast medium quickly passes in to the urine.

Retrograde pyelography: a series of x-rays done after introduction of contrast medium through a catheter inserted into the ureter.

*Other radiological procedures include: Fluoroscopy-*a technique for producing a temporary image on a screen. The radiologist moves the screen up and down the patient's body and observes what is happening within selected parts of the body. This is especially useful for identifying restricted or blocked passages in the hollow organs, especially with use of contrast material. *Mammography-* (mamm(o) = breast) + (-graphy = method of recording), a technique for detection of breast cancer. Several x-ray views are taken of one or both breasts and the x-ray films are later examined for the presence of lesion. Very small, early cancers of the breast can be diagnosed using this technique, before they can be felt by physical examination. *Xeroradiography:* (xero- = dryness) + (radio = radiation) + (-graphy = method of recording), a technique using the same image producing process as the Xerox copier machines. The xeroradiography machine can produce either a positive or negative picture on specially coated white paper that can be read in any light. Today, this is used for x-rays of the skull, limbs and breast as well as the cervical spine. *Thermography:* (thermo = heat) + (-graphy = method of recording), a technique for detecting cancer by differentiating regions of hot and cold temperature in the body. The surface temperature (its infrared radiation) is photographically recorded. The thermogram is a mosaic of many thousand bits of temperature information displayed photographically in shades of gray. The (increased emission of heat); the darker tones indicate cool areas. Since cancer cells usually divide more rapidly than

normal cells, they often give off more heat than normal surrounding cells.

- c. *Ultrasound*: Diagnostic ultrasound is relatively new technique for visualizing internal structures of the body by recording the reflection of ultrasonic waves (high frequency sound waves) or echoes as they interact with various tissues of the body. Different densities in tissues can be distinguished from cystic masses and solid masses. The record produced is called an ultrasonogram or an echogram. Examples are: Pelvic ultrasound-to visualizes the uterus, fallopian tubes, ovaries and other pelvic organs. Ultrasound of the liver, gallbladder and pancreas. Ultrasound of the kidneys. Ultrasound of the breasts.
- d. *Diagnostic nuclear medicine*-This is an imaging technique whereby a radioactive substance known as a radioisotope is administered to a patient to diagnose disease. As the radioisotope disintegrates, it emits gamma rays from within the body and these are photographically recorded by a scanner. The photographic record is referred to as a scan. This differs from x-ray procedures where the x-rays are passed through the body from an external source.

Sometimes non-radioactive compounds are labeled or tagged with a radioactive isotope and sometimes radioactive tracers (radioactive pharmaceuticals) are given by mouth or by vein. Some of the isotopes are selectively absorbed by tumors or by specific organs in the body. The concentrated radioisotopes outline the tumor or organ, making it visible on the scanner by emission of radioactive energy. The more common scans are: bone, kidney, thyroid, heart, lung, liver, spleen, brain, and total body scan.

- e. *Computerized tomography scan (CT scan)*: In this method, a picture is produced of all the structures in one plane (or slice) of the body. It is done by passing x-rays through the body in this plane and, from the readings; a computer constructs an image, which is displayed on a television screen where it can be photographed for a permanent record. The precision of the scanner permits a more accurate diagnosis of the extent of the disease than most other means. It can discover tumors at an early stage and pinpoint their exact location. CT scans can be used with or without the use of contrast media. Examples are: CT scan of head, lung and upper abdomen.
- f. *Magnetic resonance imaging*: This is a non-invasive imaging technique which does not expose the patient to ionizing radiation and permits delineation of tissue without the use of contrast enhancing agents. The MRI scans do not visualize bone. Hence, the soft tissue adjacent to bone is easily viewed.
- g. *Endoscopy*-This diagnostic procedure involves the use of specific instruments (scopes), which enable one to view the interior of the body. Endoscopes may be either rigid metal or flexible fiberoptic tubes. Diagnoses arrived at through endoscopy without microscopic confirmation will be included in the category of exploratory surgery, although not all such examinations require a surgical

incision. If a lesion is noted, it is possible to remove tissue by biopsy (via the endoscope) for histological study. Typical endoscopy procedures include, bronchoscopy-examination of the bronchi with a scope; colonoscopy-examination of the colon and rectum by means of an elongated, flexible fiberscope. Colposcopy-examination of the cervix and vagina under magnification. Cystoscopy-direct visual examination of the interior of the urinary bladder. Oesophagoscopy-direct visualization of the interior of the esophagus. Gastrosopy-direct visual examination of the interior of the stomach. Laryngoscopy-examination of the interior wall of the larynx. Otoscopy-inspection of the inner ear. Proctoscopy-inspection of the rectum, with the aid of a tubular endoscope with appropriate illumination. Rhinoscopy-direct examination of the nasal passages either through the nostrils (anterior rhinoscopy) or through the nasopharynx (posterior rhinoscopy). Sigmoidoscopy-direct visual examination of the sigmoid colon by means of an instrument, which can visualize up to 25cm from the anal verge. Urethroscopy-visual inspection of the interior of the urethra. In all of the “-oscopies” described so far, the scope has been inserted through a natural opening in the body. However, in the following endoscopic examinations, an actual incision is made through which the instrument is inserted into the body space to be examined.

Mediastinoscopy: examination of the mediastinum by means of a tubular instrument permitting direct inspection of the area between the lungs.

Peritoneoscopy: examination of the peritoneal cavity by an instrument inserted through the abdominal wall.

Thoracoscopy-direct examination of the pleural cavity by means of an endoscope, which is inserted into the cavity through an intercostals space.

- 3 *Exploratory surgery/autopsy*-The diagnosis is based on findings during surgical exploration, by direct visual examination or palpation, or on the results of a post-mortem examination (autopsy), without microscopic confirmation (also called provisional anatomical diagnosis of malignancy or PAD). When suspected cancer of an internal organ has been located, exploratory surgery may be performed to determine the exact nature of the cancerous condition and the extent of the disease or the degree to which other organs or structures within the observed area are affected. In most instances, biopsies will be done and specimens examine microscopically, in which case the diagnostic method falls into group B, ‘Microscopic methods’.
4. *Specific biochemical and/ or immunological test*-There are substances, which can be measured in blood (or other body fluids), which may be helpful in the diagnosis of cancer.

a. Serum alpha-foeto protein (AFP) is a substance normally present in the tissues of the foetus and which disappears or is greatly reduced in amount after birth. High levels of AFP in the patient’s blood suggest the presence hepatocellular carcinoma or teratocarcinoma. AFP is synthesized by the tumor cells themselves and secreted by them in the blood. A drop in the AFP level indicates regression of the tumor. Hence, AFP is valuable for diagnosis as well as for monitoring response to treatment or the development of recurrence.

b. *Beta-subunit of the human chorionic gonadotrophin (Beta-HCG)* is a placental antigen, which is present in the serum of all patients with tumor arising in cells of the placenta (especially choriocarcinoma), in a majority of patients with germ cell tumors of the testis and ovary, and to some extent in patients with other cancers. Serial measurement of Beta-HCG is of importance in the diagnosis and follow-up of cases of choriocarcinoma. For example, a very high level of Beta-HCG in a patients points strongly to the presence of choriocarcinoma; if after chemotherapy the level of Beta-HCG goes down to normal, one can say that the patient responded to the treatment, and a later increase in the level of Beta-HCG is indicative of reactivation of the tumor. The normal value of Beta-HCG is 0-5 units/ml.

c. *Serum acid phosphatase*: elevated levels of acid phosphatase in the serum are noted in 85% of patients with cancer of the prostate with metastases to the bones, but in only about 20% of cases which remain localized in the prostate gland. Acid phosphatase determination can be used to determine whether prostate cancers are suitable for surgery. The normal value in the serum depend on the method used in determining the acid phosphatase level, as in:

A.	Bodansky:	0.5-2.0 units
B.	King-Armstrong	1-5 units
C.	Bessey-Lowry:	0.1-0.63 units
D.	International units:	0.2-1.8 units/l

(NOTE: the normal values are given as guide. Registry clerks need not memorize these values but should be aware of the normal values in the hospital where they are working.

d. *Serum alkaline phosphatase*: the levels of this enzyme in the blood increase when there is destruction of cells. It is produced in the liver and bones, and an elevated alkaline phosphatase is indicative of bone and liver abnormalities. The normal value depends on the method used in determining the alkaline phosphatase level such as:

Bodansky	Adults:
King-Armstrong	Adults:
International units	21-91 u/l
Children	5-14 units
Children	15-20 units

e. *Lactic acid dehydrogenase (LDH)*: this is an enzyme, which occurs in many body cells. An elevated LDH indicates increased cell destruction, possibly following metastasis.

f. *Carcinoembryonic antigen (CEA)*: this is a protein, which is normally present in endodermal tissues (the innermost of the primary germ layers of the embryo) during the first six months of fetal life. It was first noted to be present in colorectal cancer and was initially thought to be specific to cancers of the gastrointestinal tract. However, studies have shown that CEA is elevated not only in GI tract malignancies but in other malignancies and in non-malignancies and in non-malignant conditions. At present, its most useful application is in predicting the outcome of disease (prognosis) and in the follow-up of response to treatment, and checking for development of recurrence.

- g. *Fetal sulfoglycoprotein antigen (FSA)*: this antigen is associated with gastric cancer. It is observed in a majority of patients with gastric cancer and in 3 to 7% of individuals aged 45 to 70 without gastric neoplasm.
- h. *Pancreatic oncofoetal antigen (POA)*: this is an antigen associated with pancreatic cancer.
- i. *Human placental lactogen (HPL)*: this is polypeptide synthesized by cells of the human placenta. HPL is demonstrable in the sera of majority of patients with choriocarcinomas and in certain patients with germ cell tumors of the ovary and testis.
- j. *Tissue or organ-associated antigens*:
 - i. Cervical cancer antigens: associated with cancer of the cervix uteri;
 - ii. Ovarian cancer antigen (CA 125): associated with carcinoma of the ovary;
 - iii. Breast cyst fluid protein: associated with breast cancer;
 - iv. Lung tumor antigen: associated lung cancer
 - v. Leukaemia-associated antigens: associated with acute leukaemia
 - vi. Prostatic-specific antigen (PSA): associated with carcinoma of prostate.
- k. *Ectopic hormones*
 - i. calcitonin: associated with medullary carcinoma of thyroid gland
 - ii. parathormone: associated with small cell lung cancer;
 - iii. 'big' ACTH: associated with small cell lung cancer.
- l. *Antigens of oncogenic viruses*:
 - i. Human papilloma virus (HPV): certain types are associated with carcinoma of the cervix uteri;
 - ii. Epstein-Barr virus: associated with Burkitt's lymphoma and nasopharyngeal carcinoma;
 - iii. Mouse mammary tumor virus: associated with breast cancer.
- m. *Normal antigens or their variants*:
 - i. ferritin: associated with breast cancer
 - ii. casein: associated with breast cancer
 - iii. ceruloplasmin: associated with a variety of cancers;
 - iv. immunoglobulins: associated with multiple myeloma, Waldenstrom's macroglobulinaemia;
 - v. blood group substances: associated with a variety of cancers;
 - vi. lactoferrin: associated with lung cancer;

- vii. tissue polypeptide antigen (TPA): associated with a variety of cancers.

Microscopic Methods

The microscopic methods of diagnosis include:

Cytology: the microscopic examination of cells, usually contained in fluid which bathes a suspected cancer; and

Histology: the microscopic examination of tissues removed from the suspected cancer itself or from its spread (metastasis).

The purpose of microscopic examination is to determine characteristics of the tissues and cells, to see whether they are indicative of a malignancy.

5. *Cytology or hematology*

- a. *Cytology*: (cyto = cells) + (-logy = study of), the study of cell structure, function and pathology. Cells are continuously being shed (exfoliated) from tissues that line body cavities and hollow organs of body. These exfoliated cells may float in the fluid or mucous material, which bathes or passes through these cavities. The microscopic examination of these cells to determine whether they are malignant or not and to determine their tissue of origin is known as exfoliative cytology.

There are some body cavities, which can be checked for fluid, such as the pleural cavity, and the peritoneal cavity. Normally, the fluid in these cavities is limited to an insignificant lubricating layer that cannot be aspirated. Therefore fluid in these cavities, which can be aspirated, indicates a pathological process such as malignancy or infection. Listed below are some of the sources of specimens for cytological examination:

- Sputum
- Bronchial washing or bronchial brushing
- Tracheal washing
- Pleural fluid
- Gastric fluid
- Spinal fluid
- Breast secretion
- Prostatic secretion
- Urine sediment
- Cervical and vaginal smears
- Bone marrow aspiration
- Peritoneal fluid

There are several procedures employed to obtain material for cytological examination, including the following

- i. Swabs: use of swab or similar device to obtain fluid and secretions, which can be used to make a smear. Example: cervical smear.
- ii. Brushings: the lining of an organ is brushed for the purpose of obtaining cells. Example: gastric brushing; bronchial brushings
- iii. Washings: instillation of fluid into a hollow organ or structure and removal of the fluid for the purpose of collecting any cells, which have been exfoliated in the fluid. Example: gastric washing

- iv. Scrapings: the lining of a structure or organ is scraped with an instrument for the purpose of obtaining cells. Example: cervical smear, using an Ayre's spatula or cerviscraper
- v. Punctures: insertion of a needle into a cavity or organ for the purpose of removing some portions of the content (fluid, bone marrow, tissue). Examples:
 1. paracentesis: surgical puncture of a cavity for aspiration of fluid
 2. paracentesis abdomini: puncture of the peritoneal cavity
 3. thoracocentesis: puncture of the pleural cavity

The Papanicolaou classification of cells for detection of malignancy is as follows:

Class Interpretation

- I No evidence of a malignant neoplasm, no atypical cells
- II Atypical cells present but no evidence of malignant neoplasm
- III Cells present causing suspicion of malignant neoplasm
- IV Fairly conclusive evidence of malignant neoplasm
- V Conclusive evidence of malignant neoplasm

- b. *Hematology*: (haema- = blood) + (-logy = study of), the microscopic examination of the cells of the blood or blood-forming tissues (especially bone marrow), looking for changes in these structures and/ or number of various types of blood cells, including immature cells.

There are three main types of blood cells:

- erythrocytes: (erythro = red) + (-cyte = cell), or red blood cells;
- leukocytes: (leuko = white) + (-cyte = cell), or white blood cells;
- thrombocytes: (thrombo = thrombus or clot) + (-cyte = cell), or platelets, the cells concerned with clotting of the blood.

- i. **Red Blood Cells (RBC):**

These contain haemoglobin, a blood protein responsible for the transport of oxygen from the lungs to the tissues and the transport of carbon dioxide from the tissues to the lungs.

There are several forms of immature or very young erythrocytes, namely:

- pronormoblast: the earliest precursor of red blood cells
- normoblast: nucleated red blood cell
- reticulocyte: a young erythrocyte (one-to two-day old red blood cell)

The reticulocyte count is a useful measure to determine whether anaemia is due to decreased production of red cells or due to increased destruction of red cells or due to increased destruction of these cells. A significant

increase in the number of reticulocytes in the blood cells from the bone marrow, usually suggestive of increased cell destruction or haemolysis:

(haemo=blood) + (-lysis=destruction). In contrast, a failure to produce red blood cells is reflected in a very low reticulocyte count.

Anaemia: (an-=without) + (-aemia=blood), a deficiency in the number of red blood cells or deficiency in the haemoglobin content of the red cells. This is characterized by pallor of the skin and mucous membranes and may be associated with becoming tired easily, dizziness or fainting spells.

j. White blood cells:

There are five types of circulating white blood cells:

-neutrophil	}	granular leukocytes
-eosinophil		
-basophil		
-lymphocytes	}	agranular leukocytes
-monocytes		

Neutrophils: these white blood cells contain very small purplish granules in their cytoplasm. The mature form has segmented nuclei. Hence, this cell is also known as: polymorphonuclear leukocytes ('polymorph'). The immature forms of a neutrophil are:

- stem cell
- myeloblast
- promyelocyte
- myelocyte
- metamyelocyte
- band or stab cells

Normally, neutrophils are not released to the peripheral blood unit they have matured beyond the metamyelocyte or 'band' stage. Neutrophils usually comprise about 40-60% of leukocytes in the peripheral blood.

Eosinophils: these are granular leukocytes with large reddish granules in the cytoplasm. They develop in the bone marrow just like neutrophils. Eosinophils comprise about 1-3% of leukocytes.

Basophils: these granular leukocytes have large bluish granules in their cytoplasm. They mature in a similar fashion to the neutrophils. Basophils are the least common of leukocytes, comprising only about 0-1%.

Lymphocytes: these are agranular leukocytes with a small amount of bluish cytoplasm. They comprise about 20-40% of

leukocytes. Analyses of these cells have shown that there are two types, the T and the B Cells.

Monocytes: these are granular leukocytes with phagocystic and bactericidal capacities. They comprise about 4-9% of all white blood cells.

k. *Platelets (throbocytes)*

These are tiny cells or discs whose primary function is haemostasis (clotting of blood). Peripheral blood is circulating blood obtained from blood vessels or the extremities. This may be obtained through a finger prick or through a venipuncture (specimen taken directly from a peripheral vein). The common examinations for peripheral blood include: complete blood count (CBC), platelet count, reticulocyte count and peripheral smear.

In examination of the peripheral blood, the peripheral smear is the most important. Examination of the peripheral smear shows the size and color of the red blood cells, their variations in size known as anisocytosis: (an-=without) + (iso=equal-) + (cyto=cell) + (-osis = increase), or variation in shape referred to as poikilocytosis; (poikilo-=irregular) + ((cyto = cell) + (-osis = increased number), which are helpful in the diagnosis of specific anaemias. Normally, immature forms of leukocytes are not found in the peripheral blood. Hence, a markedly increased leukocyte count with a number of immature forms, especially 'blasts', alerts one to the possibility of leukemia.

Certain types of conditions associated with abnormality of the blood cells are:

Anaemia: deficiency in erythrocytes or haemoglobin

Aplastic anaemia: a form of anaemia in which there is lack of formation of blood cells in the bone marrow.

Leukaemia: a malignant disease of the blood and the blood-forming organs characterized by uncontrolled proliferation of leukocytes, which is diagnosed by microscopic detection of abnormal cells

Leukocytosis: increase in the number of leukocytes in the blood

Leukopaenia: reduction in the number of leukocytes in the blood

Polycythaemia: excessive number of erythrocytes

Thrombocytopenia: decrease in the number of platelets

A table of normal values for blood examinations is given below. The registry personnel are not expected to memorize these values. They are given as a guide for abstracting haematological reports. The diagnosis of haematological malignancies by peripheral blood examinations is often based on an abnormal cell count (usually a markedly elevated white blood cell count (WBC) and the presence of immature cells in the smear. Registry personnel should have a basic knowledge

of what is normally expected in complete blood count examinations and peripheral smears in order to be able to recognize values, which are abnormal.

Bone Marrow Studies are essential in the diagnosis of a wide variety of haematological disorders, especially leukaemias. The circulating blood cells are actively produced in the bone marrow. A bone marrow sample can be obtained by needle aspiration or by biopsy of bone marrow, and is considered as a histological examination (see 6/7 below)

Haematocrit	Men Women	42-52% 37-47%
Haemoglobin	Men Women	140-180 Gms/litre 120-160 Gms/litre
Erythrocytes (RBC)	Men Women	4.5-6.3 x 10 ¹² / litre 4.2-5.4 x 10 ¹² / litre
Reticulocyte count:		0.5-2% of red blood cells 5 x 10 ⁹ – 10 x 10 ⁹ / litre
Leukocytes (WBC):		0.5 -2% of red blood cells 5 x 10 ⁹ – 10x 10 ⁹ / litre
Neutrophils:		40-60%
Band (stabs):		0-5%
Juveniles:		0-1%
Myelocytes:		0%
Eosinophils:		1-3%
Basophils		0-1%
Lymphocytes		20-40%
Monocytes:		4-8%
Platelet count:		200-500 x 10 ⁹ / litre

(6) *Histology of metastasis*

Histology: (histo = tissues) + (-logy = study of), the microscopic Examination of tissues removed from a site of spread (metastasis) of cancer. The examination may be made using tissue obtained from a biopsy (the removal and examination – both gross and microscopic – of tissues from a living body for the purpose of diagnosis), or from an operative or surgical procedure. If the source of the specimen is from a suspected metastatic site, it is known as histology of the metastasis.

(7) *Histology of primary tumor*

If the source of the specimen is from the suspected origin of the malignancy, it is known as histology of the primary.

(8) *Autopsy*

This refers to the examination of the body after death, and involves the removal and examination (gross and microscopic) of organs and tissues from the body, to establish the diagnosis or to determine the cause the death. It is also known as necropsy or post-mortem examination.

There are usually two types of reports made following autopsy:

- a. the Provisional Anatomical Diagnosis (PAD), is arrived at through the gross (= macroscopic) examination findings at autopsy, not confirmed microscopically; and
- b. the Final Anatomical Diagnosis (FAD) is arrived a through microscopic examinations of tissues removed at autopsy. This is the most important portion of the autopsy report. It could confirm the diagnosis of cancer made clinically. It can determine the origin of the cancer (primary site) and its histological type. It can also give an accurate assessment of the extent of spread of the malignancy.\

Treatment

Treatment for patients with cancer may either be cancer-directed or non-cancer directed.

(1) Cancer-directed treatment

Definitive cancer-directed treatment is a specific therapy which modifies, controls, removes or destroys cancer tissue. This may be directed towards a primary or towards a metastatic site. Treatment may be considered as definitive cancer-directed therapy, even if it is not considered curative for a particular patient because of the extent of disease, failure to complete treatment or lack of response. Definitive cancer-directed therapy may be either curative, adjuvant or palliative.

- (a) Curative treatment is aimed at completely eradicating an existing disease.

Examples are:

- Total hysterectomy for early endometrial cancer:(hystero = uterus) + (-ectomy = surgical removal)
- Modified radical mastectomy for early breast cancer: (mas = breast) + (-ectomy = surgical removal)
- Total thyroidectomy for papillary cancer of thyroid: surgical removal of whole thyroid gland.
- Abdomino-perineal resection for rectal cancer: surgical removal of anus and rectum and creation of a permanent colostomy.

- (b) Adjuvant treatment is given to enhance the effectiveness of another form (modality) of treatment.

- Adjuvant chemotherapy for breast cancer after mastectomy.
- Adjuvant radiotherapy for cervical cancer after hysterectomy.

- (c) Palliative treatment may modify, control, remove or destroy cancer tissue but does not attempt to cure.

- Palliative resection of colorectal cancer.
- Palliative radiotherapy for advanced breast cancer
 - Palliative chemotherapy for advanced lung cancer.

(2) Non-cancer directed treatment

Non-cancer directed therapy may also be given to cancer patients to relieve symptoms and alleviate pain and distress but such therapy does not treat the cancer.

This includes palliative (non-cancer-directed) treatment, to relieve symptoms such as obstruction without attempting to cure. Examples are:

- 'By-pass' operations to relieve obstruction by forming a connection (anastomosis) between two normally separate organs. Examples of this are gastro-jejunostomy (anastomosis of stomach and jeju-num) to relieve obstruction of the duodenum, and colostomy to short-circuit the gastro-intestinal tract when there is obstruction in the colon.

Surgical procedures to relieve pain are also included in this category:

- Rhizotomy: (rhizo=root) + (-tomy = cut), interruption of the roots of the spinal nerves within the canal to relieve intractable pain.

Supportive treatment is directed to sustaining the strength of the patient.

- Blood transfusion
- Parenteral nutrition: nutrition not through the alimentary canal but through intravenous injection.

The different modalities of cancer-directed treatment are:

- surgery
- radiotherapy
- chemotherapy
- hormone therapy
- immunotherapy

Surgery

This involves the total or partial removal of a primary tumor or its secondary site. It does not include incisional biopsy where a part of the tumor is removed for examination in order to establish the diagnosis.

- Cholecystectomy: (chole- = bile) + (cyst = sac) + (-ectomy = surgical removal), surgical removal of gallbladder.
- Gastrectomy: (gastr = stomach) + (-ectomy = surgical removal).
- Hysterectomy: (hyster(o) = uterus) + (-ectomy – surgical removal).
- Mastectomy: (mast = breast) + (-ectomy – surgical removal).
- Nephrectomy: (nephr (o) = kidney) + (-ectomy = surgical removal).
- Oophorectomy: (oophor (o) = ovary) + (-ectomy = surgical removal).
- Orchiectomy: (orchi = testis) + (-ectomy = surgical removal).
- Pneumonectomy: (pneumo = lung) + (-ectomy = surgical removal).

Surgical treatment relevant to the cancer registry includes the following:

- most “-ectomies”
- excision biopsy or extirpation
- biopsy, NOS, if there is no residual on further surgery
- electrocautery
- cryosurgery
- laser surgery
- conisation of cervical carcinoma-in-situ
- fulguration (destruction of tissue with the aid of electro-cautery) of bladder, rectrum or skin tumours (this is derived from the Latin word ‘fulgur’ meaning lightning)

Surgical treatment can be definitive or not definitive. Surgical procedures done mainly to establish diagnosis or to determine extent of disease are considered not definitive, and definitive surgery does not include the following:

- bypass surgery
- conisation of the cervix for microinvasive cancer of the cervix
- exploratory laparotomy or thoracotomy with or without biopsy
- excision of lymph nodes for diagnosis or staging
- total removal of non-cancerous endocrine glands
- paracentesis abdominis or thoracentesis
- surgery to relieve pain
- TUR without removal of tumor tissue

Radiotherapy

Ionizing radiation is delivered clinically in the following ways:

- (1) External beam irradiation from sources at a distance from the body:
 - X-rays
 - Cobalt
 - Linear accelerator
 - Betatron
 - Neutron
 - Electron
- (2) Brachytherapy: (brachy = short) + (-therapy = treatment), refers to local irradiation from sources in contact with or near target tissue:
 - introcavitary (e.g. radium insertion for cervical cancer)
 - interstitial (as in radon seed implants in breast cancer)
 - surface placement of radioactive isotopes in closed containers may be given via implants, moulds, seeds, needles, and applicators
- (3) Internal or systematic irradiation from radioactive sources (¹³¹I or ³²P) administered intravenously or parenterally. The radioisotopes used for radiotherapy are:
 - Gold (Au 198)
 - Cobalt (Co60)
 - Radium (Ra 226)
 - Radon (Rn 222)
 - Caesium (Cs 137)
 - Iodine (I 131)
 - Iridium (Ir 192)
 - Phosphorus (P32)

Chemotherapy

This involves the use of any chemical or cytotoxic drug in the treatment of cancer. The cytotoxic effect is exerted directly on the tumor and does not result from a change in the hormonal balance (hormone therapy) nor a change in the host's immune response (immunotherapy).

Chemotherapy may be:

- curative: aims to achieve a cure
- Palliative: aims to reduce the bulk of disease to relieve symptoms and to prolong life.
- Adjuvant: aims to control microscopic spread of cancer following other forms of treatment such as surgery or radiotherapy

Some of the chemotherapeutic agents used are:

Actinomycin D	L-asparaginase
Bleomycin	Lomustine (CCNU)
Carboplatin	Melphalan
Carmustine (BCNU)	6-Mercaptopurine (6-MP)
Chlorambucil	Methotrexate
Cisplatin	Mitomycin C
Cyclophosphamide (endoxan)	Mitoxantrone
Cytarabine	Nitrogen mustard
Daunorubicine	Procarbazine
Doxorubicin (adriamycine)	Semistine (Methyl-CCNU)
Etoposide (VP 16)	Thiotxepa
5-Fluorouracil (5FU)	Vinblastine
Hexamethylmelamine	Vincristine (oncovin)
Hydroxyurea	Vindesine
Ifosfamide	

Notes:

The registry personnel are not required to memorize these chemotherapeutic agents. However, they should at least be acquainted with the drugs in order to recognize them as chemotherapeutic agents if they are encountered in the process of reviewing the medical records.

These are also some non-malignant conditions which are treated with chemotherapeutic agents, e.g., psoriasis with methotrexate, systemic lupus erythematosus (SLE) with cyclophosphamide.

Hormone therapy

This is defined as the use of any type of therapy, which achieves its effect on cancer tissue through a change in the hormonal balance of the patient. Hormone therapy may be either ablative or additive.

(1) Ablative

Removal of an endocrine organ in order to achieve a change in the hormonal balance of the patient. This may be done by surgical removal of the endocrine organ as in:

- Oophorectomy: (oophor = ovary) + (-ectomy = surgical removal).
- Adrenalectomy: (adrenal) + (-ectomy = surgical removal).
- Hypophysectomy: (hypophysis) + (-ectomy = surgical removal)
- Orchiectomy: (orchid = testis) + (-ectomy = surgical removal).

The first three procedures may be employed in the treatment of breast cancer. Radiation ablation of the ovaries for breast cancer is also considered as ablative therapy.

(2) Additive

Exemplified by the use of hormones, anti-hormones or steroids for hormonal effect on cancer tissues. Examples:

- Interferon

- Interleukines
- Vitamin therapy
- Vaccine therapy (e.g. BCG)

Immunotherapy

This refers to use of any type of therapy which exercise its effect on cancer tissue through a change in hosts

REFERENCE DATE

The reference date is the effective date cancer registration starts in a specified at-risk population or in a specific facility. The reference date for the Palau Cancer Registry is January 1, 1999. Cases diagnosed on or after the reference date must be included. *Note. Palau Registry database currently has all the cases from 1995 to 2002 diagnosis.*

REPORTABLE DIAGNOSES

RPPL No. 5-33, known as the “Cancer Registry Act” defines “cancer” as “all malignant neoplasm, regardless of the tissue of origin, including malignant lymphoma disease.” COC, NPCR, and SEER require the inclusion of all neoplasm’s in the International Classification of Disease for Oncology, Third Edition (ICD-O-3) with a behavior code of 2 or 3 (in-situ or malignant), with the exception of squamous cell and basal cell carcinoma of the skin, prostatic intraepithelial neoplasia (PIN) III, carcinoma in situ (CIS) of the cervix, and cervical intraepithelial neoplasia (CIN) III. Code M9421 (juvenile astrocytoma, pilocytic astrocytoma, or piloid astrocytoma), with behavior code of 1 (borderline) in ICD-O-3, is reportable. In the best interest of the Republic, the Palau Cancer Registry is currently collecting all neoplasm with behavior code of 2 and 3 including squamous cell and basal cell carcinoma of the skin and carcinoma in situ of the cervix (CIS). During data transmission to NPCR all squamous cell and basal cell carcinoma of the skin including carcinoma in situ of the cervix (CIS) will be put on a holding file, until such time a specific database is designated for them.

MULTIPLE PRIMARY

The methods used for counting tumors affect the comparability of cancer rates among registries. It is important that identical rules have been used for counting multiple tumors in the patient whether in the same organ, or opposite sides of paired organs, in different sites or subsites and whether they were diagnosed at the same or different times. Currently, NPCR follows SEER rules for multiple primaries, and so does the Palau Cancer Registry. *Please see the “SEER Program Code Manual” for more details.*

NATIONAL PROGRAM OF CANCER REGISTRIES (NPCR) PROGRAM STANDARDS

The following are NPCR Program Standards as currently defined for the purposes of the Program Announcement. The NPCR Program Standards may change during the project period of the cooperative agreement.

1. **Legislative Authority**

(a) *The state has a law authorizing a statewide cancer registry.*

(b) *The state has legislation or regulations in support of all eight criteria specified in Public Law 102-515.*

2. **Data Content and Format**

- (a) *The information collected or derived on cancer cases includes all data elements currently required by the NPCR.*
- (b) *The data codes for all required and recommended data elements are consistent with those currently prescribed by NPCR.*
- (c) *The state central registry uses a standardized, NPCR-recommended data exchange record layout for the exchange of data.*

3. **Data Completeness**

- (a) *Within 12 months of the close of the diagnosis year, 90% of expected, unduplicated cases are available to be counted as incident cases at the central cancer registry (CCR)*
- (b) *Within 24 months of the close of the diagnosis year, 95% of expected, unduplicated cases are available to be counted as incident cases at the central cancer registry*
- (c) *Within 24 months of the close of the diagnosis year, the state has performed death clearance, and 3% or fewer of cases in the database are reported by death certificate only at the central cancer registry.*
- (d) *Within 24 months of the close of the diagnosis year, (one) 1 or fewer duplicate cases per 1,000 are present in the database at the central cancer registry.*
- (e) *The central registry performs death clearance and follow-back.*

4. **Data Timeliness**

- (a) *Within 12 months of the close of the diagnosis year, 90% of expected, unduplicated cases are available to be counted as incident cases at the central cancer registry.*
- (b) *Within 24 months of the close of the diagnosis year, 95% of expected, unduplicated cases are available to be counted as incident cases at the central cancer registry.*
- (c) *Within 24 months of the close of the diagnosis year, the state has performed death clearance, and 3% or fewer of cases in the database are reported by death certificate only at the central cancer registry.*
- (d) *Within 24 months of the close of the diagnosis year, (one) 1 or fewer duplicate cases per 1,000 are present in the database at the central registry.*

5. **Data Quality**

- (a) *Within 12 months of the close of the diagnosis year, 97% of cases pass an NPCR-prescribed set of standard data edits.*
- (b) *Within 24 months of the close of the diagnosis year, 99% of cases pass an NPCR-prescribed set of standard data edits.*

Annual Report

Within 12 months of the end of the diagnosis year (and with data at least 90% complete), the state produces an annual report (hardcopy or electronic). The annual report includes, at minimum, age-adjusted incidence rates and age-adjusted mortality rates for diagnosis year

by sex for selected cancer site and, where appropriate, by sex and race and ethnicity for selected cancer site.

Data Use

Within 24 months after the completion of the diagnosis year, an analytic data set that meets NPCR standards for data completeness and quality is available for research purposes.

Data Monitoring

The state annually submits and analytic data file to CDC with individual records containing all requested data elements.

DATA COLLECTION

Case-finding

Case finding is the system used for locating every new cases of cancer that comes from the area covered by the registry, and which is diagnosed and/or treated on or after the registry's reference date (the date the registry began collecting data on cancer), January 1, 1999. Case finding procedures are performed before actual abstracting of data. The main sources of information on cancer cases includes the Referral Program Logs, MOH Public Health Database, Doctors' Logs, HIS Database, BCCEDP Database, Death Certificates File & Database, Laboratory Logs, and X-Ray Logs. In addition to there are two private clinics (Family Surgical Clinic & Belau Medical Clinic) currently reporting.

Following details specific procedures for each case-finding sources.

- A. *Referral Program Logs*-Involves reviewing the Referral program logbooks for possible off-island referral to St. Lukes Medical Center and Tripler Army Medical Center. Referral may be for diagnosis, treatment, or follow-up of cancer. Registry personnel should work closely with the Referral Coordinator to make sure additional information regarding cancer referrals is reported to the Registry on a monthly basis.
- B. *HIS Database*-The Health Information Database is another good source of information to the Registry. This requires querying the HIS Database to get specific reports on patients who are diagnosed with cancer. Currently, the registry has access to the Health Information System database through the local network. In the event, the Registry could not obtain report through the querying system; a copy of such report can be requested by the Public Health Data Management staff.
- C. *BCCEDP Database*-Requires querying the BCCEDP CaST database for patients diagnosed with breast and cervical cancer. All copies of breast & cervical cancer pathology reports are also kept in the Registry files for the case-finding purposes.
- D. *Death Certificates*-Involves review of hard copy of death certificate file for a given year. This file is available at BNH Medical Record at all times for registry staff to review. The Health Information System database can also be used for vital status verification. Modules for this type of verification are available in the Registry's computers that are connected to the local area network as well. Death certificate results can also be obtained by the epidemiologist as her work involves reviewing death records, for mortality studies. This process helps avoid duplicate efforts and helps save up time for the Registry.
- E. *Laboratory Logs*- This requires the registry personnel to review the laboratory logbooks for elevated tumor markers. A list of patients with elevated results is generated on a monthly

basis and checked against the Registry database. If elevated tumor markers are part of follow-up procedures, they are used to update the laboratory information section of the patients' record in the Registry database. The result is also checked to make sure it does not suggest another primary site for that patient. For all other patients with elevated tumor markers, Registry personnel will crosscheck with medical records to see if they yield possible new cases. If so the name will be part of the master list to be abstracted. If there is no indication that the abnormality yields a diagnosis of cancer the name is taken off the list.

- F. *X-Ray Logs*-X-Ray logbook is another method for determining the extent of the disease. Unfortunately, the current logbook fields do not show useful information that can be used to assess disease stage. Registry personnel can use radiology reports found in patient's medical record to verify if the activity is done as part of cancer screening.
- G. *FSC & BMC*-Normally the Doctors submit patients name to the Registry. In some instances the Registry personnel may be required to submit a request to the Doctors as a reminder. In most cases, it is very hard to do a one-on-one interview with private clinic physicians, so the best solution is for them to just list the names of all patients they have diagnosed for cancer. This list will be part of the overall list for abstraction.
- H. *Pathology Reports*-Often times pathology reports are sent to the Registry from the private clinics. Doctors also report by sending copies of the pathology report to the Registry. Also all the pathology reports area available in patient's medical record/charts.

Data Abstracting

After identifying all cases with reportable diagnosis, the list is sorted by their vital status to form two sets, alive and death. There is no particular order on which set to abstract first, however, it is recommended that each set be abstracted completely before moving to the other set. The main reason for this is to smooth out the process in medical records department. The registry personnel are now ready to abstract details from patient's records.

b. *BNH Medical Records*-When Registry personnel are ready to abstract details from medical records, a registry contact in medical records is notified and a list is furnished to her so she can start pulling out records. Depending on which set to start with, it is recommended that active records be abstracted within the vicinity of medical records, as active records should be readily available in medical records section at all times, in case patient pays visit to the hospital. However, due to space availability in the Medical Records office, active medical records may be brought to the Cancer Program office for abstraction. To ensure availability of active records, registry staff can only have the records during normal working hours. Registry staff must return all medical records to the Medical Records Department at the end of the day which is 4:30p.m. Death records can be taken to Cancer Program's office for abstraction but all policies in regards to confidentiality should be enforced. In some instances, active medical records may be brought to the Cancer Program office to be abstracted. This may only happen due to lack of office space or if the process interferes with daily operations of the medical records department. Details of each record are recorded on a standard registry abstract form before being registered in the database.

c. *Private Clinic's Medical Records*-Private clinics also report cases in a form of pathology report. In other cases, where pathology report is not available, but is indicated on the abstracting list, the Registry personnel should work out a schedule with each private clinic before going in. Additional information may also be obtained at the BNH Medical Records. At the private clinics, information is abstracted using a standard registry form. All abstracting activities will be performed strictly within each clinic, regardless of record status, whether active or inactive.

SOFTWARES

Abstract Plus

Abstract Plus is an abstracting tool used to summarize the medical record into an electronic report of cancer diagnosis and treatment by abstractors and other individuals or groups who work with cancer data. This software was developed at the Centers for Disease Control and Prevention (CDC), Division of Cancer Prevention and Control (DCPC), in support of CDC's National Program of Cancer Registries (NPCR). All data items in national standard data sets, including text, are supported.

SEER*Stat

The SEER*Stat statistical software provides a convenient, intuitive mechanism for the analysis of SEER and other cancer-related databases. It can be used to view individual cancer records and to produce frequency, rate, and survival statistics. These statistics are useful in studying the impact of cancer on a population.

SEER*Prep

The SEER*Prep software converts ASCII text data files to the [SEER*Stat](#) database format, allowing you to analyze your cancer data using SEER*Stat. SEER*Prep performs two main functions: it converts text data to the specific binary format required by SEER*Stat, and it creates the SEER*Stat data dictionary. SEER*Stat 5.2 or later is required to analyze any database generated with SEER*Prep 2.3.2. SEER*Prep can be used to convert incidence, mortality, expected survival, and standard population data stored in one of the formats listed below. The [Input File Formats](#) section contains more specific information about these file formats and general rules that must be followed when creating input data files.

SPSS

SPSS for Windows provides a powerful statistical analysis and data management system in a graphical environment, using descriptive menus and simple dialog boxes to do most of the work for you. Most tasks can be accomplished simply by pointing and clicking the mouse. SPSS is one of the available tools that can be used by Registry staff for data analysis and report writing.

DATA CODING

Currently, the Registry is involved in three forms of classification for diseases. (1) the International Classification of Disease (ICD-9), (2) the International Classification of Disease (ICD-10), (3) and the International Classification of Diseases for Oncology, (ICD-O-3). As a minimum, the Registry should classify tumors as to:

- (i) their primary site or anatomical location,
- (ii) their histological type or morphology, and
- (iii) behavior

In order to do this, ICD-O is used. The Registry also code death cases. This can be done using the ICD-9 and ICD-10 causes of death. Beginning in 1999 all deaths is coded using the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10). Currently, the Registry is converting ICD-9 cause of dead on dead certificates to ICD-10, before entering into the database.

DATA INPUT PROCEDURES

After collected data are coded they are now ready to be registered in the database. The Registry uses a program called "Abstract Plus" to register new cases and update existing cases.

- a. Registration of a new patient-When a new patient is identified and an abstract for completed, a new record is created on the database. An accession number is assigned and is used to identify the patient. The accession number is the use of first four digits for year of diagnosis, followed by number allocated serially as new cases are registered in the database. Once a record is created, all information relating to that particular patient are entered and saved.
- b. Second Primary-If a new primary tumor is identified in an individual who is already registered in the database, a new registration has to be created. That means a new record in the database. It is important that the new registration be assigned a sequenced number in order to identify multiple primaries. The registry follows SEER rules when coding multiple primaries.
- c. Updating records-The Registry updates its database whenever information is available. New information linked to a case in the dbase is used to update the existing record as well. Any information that comes up before the actual follow-up process will be checked for validity before records in dbase are updated. This is the same for death certificate notifications. Death clearance is also performed annually to make sure information in database is accurate and consistent. *See Data Follow-Up Section for more details.*
- d. Editing-All records are checked for completeness and consistency as soon as data are being entered into the dbase. Usually error sign will show if data entry or coding is not consistent to critical field of edits. A registry personnel can double check information in abstract form to verify error. If error requires the personnel to see medical records, it is flagged and saved to a list of records with errors to be corrected later.

DATA MAINTENANCE & STORAGE

As soon as data are entered into the registry, all files are checked for completeness and consistency by using CDC edits built in to the database. All files have to pass certain critical field edits in order for them to be exported. Missing records, records with errors and unreportable diagnosis are contained in a Holding File. Missing records and records with errors will never reach Exporting File until sufficient information is collected, and the record pass the CDC edits.

The Registry stores and back-up its data electronically. Abstract Plus is configured to remind users to back-up at the end of each session. At the end of each session, diskettes and its contents are overwritten to absorb the new changes made or new cases registered to the database.

DATA FOLLOW-UP

The registry practices active follow-up enquiries, done once a year on the anniversary dates of the patient's diagnosis, about each patient not known to be dead. When the date of follow-up arrives a registry personnel simply ask for the record from medical record staff or goes in to the private clinics to check if there's any new information about the patient. All updates are abstracted and are used to update records in the database.

DATA QUALITY CONTROL

It is very important that the registry data be reliable and of good quality. The aim is to record all cancer cases occurring within the geographic area, by ensuring data sources for the registry is covered completely. Each abstract is carefully checked to determine its eligibility too. The incidence date is also abstracted carefully to ensure it is on or after the reference date of the registry. The registry also screen for duplicates over and over again to avoid multiple registrations as it could inflate the incidence rates. Another method used by the registry is the use of death certificates as a method to evaluate completeness. Death certificates are used as record updating tools as well as a tool used to screen for missing cases. Nevertheless, the most important tool used to ensure quality of data in the registry is the use of CDC interactive edits. A record has to pass

certain edits in order to be exported and so this tool is very helpful in making sure right combination of codes for primary site, morphology and behavior is in use. Bottom line, quality of the Registry data should adhere to Section 5 Data Quality, of the NPCR Program Standards.

DATA CONFIDENTIALITY

The following procedures should be followed in order to adhere to Section 5, Confidentiality of the Cancer Registry Act, RPPL 5-33.

- a. Data Collection-information on cancer patients is gathered actively including two private clinics. The contents of data gathered and reports should not be disclosed to other parties than the data source and the registry. Since most data are collected actively, it is the responsibility of the registry staff to preserve the confidentiality of information on cancer cases or anything of a personal or confidential nature seen or heard at the source. Data should not be left at a place where an unauthorized person(s) can gain access.
- b. Data transmission-transmission of data to NPCR via Internet goes through a detailed process. First, the computer-based database requires user identification and a password. Second, data transmission to NPCR requires that no identifying information must be included. A specific “extractor” program provided by CDC is used throughout this process to isolate identifying information before exporting to NPCR website.
- c. Data access-In the registry, all information is kept in a computer. Access to the data is protected by the use of password to windows and password to the dbase program used to register cases. Currently, access is limited to three people, the Cancer Program Administrator, and the Registry Coordinator, and Registry Technician. Additional measures are taken to ensure confidentiality for information on paper files.
- d. Data Use and Release-Please See the “Cancer Registry Act” Section 5, Confidentiality & Section 6, Disclosure as stated in RPPL No. 5-33, effective August 4, 1999. In the event a request is made to the Registry, requesting reports & data items of non-confidential nature, request letter should be addressed to the program Administrator. Upon approval the Registry personnel will produce requested reports. This process helps to ensure data is free of identifying information before being disclosed. Information requested should be used solely for the purpose as stated on the request form. Other use of the data is strictly forbidden unless otherwise specified.