pennsylvania
DEPARTMENT OF HEALTH

PENNSYLVANIA CANCER REGISTRY

Prevention, Control and Research
Commonwealth of Pennsylvania
Department of Health

Tom Corbett, Governor

2011

PENNSYLVANIA CANCER REGISTRY REPORTING MANUAL FOR NON-HOSPITAL FACILITIES

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PREFACE

PREFACE

The rate of new cancer cases in Pennsylvania is among the highest in the nation. More than 70,000 Pennsylvania residents are diagnosed with cancer each year. Without information on these new cases of cancer, it is difficult to plan prevention, education, screening, early detection, treatment, and rehabilitation programs. The Pennsylvania Cancer Registry (PCR) records the incidence of cancer for the Commonwealth of Pennsylvania and provides data to help physicians, researchers, and other health professionals plan and evaluate cancer programs.

Probably not surprising to learn is the impetus for the PCR was public concern about excess radiation exposure to persons living near a nuclear-powered utility plant. What might be surprising, however, is this plant was not the Three Mile Island nuclear plant; site of the 1979 accident, but rather a plant located at Shippingport, Pennsylvania, and the year was 1973.

Then Governor Milton Shapp appointed a committee of epidemiologists and radiation physicists to examine the question of possible increased risk of cancer for individuals residing near the nuclear-power plant. That committee reported in 1974 no conclusions could be reached due to the absence of reliable data. As a result, a task force of physicians and laypersons was appointed to examine the Commonwealth's role in helping to combat cancer, specifically emphasizing consideration of a statewide cancer registry. In 1976, the task force published a report with several recommendations for cancer control, including mandating a statewide population-based cancer incidence registry and requiring cancer be made a reportable disease.

In 1977, legislation was introduced which proposed funding for cancer research and control programs in the Commonwealth. The Pennsylvania Cancer Control, Prevention, and Research Act, Act 224 (see *PCR Manual Appendix A, Pennsylvania Cancer Control, Prevention and Research Act)* was signed into law on December 18, 1980. Passage of the bill into law resulted from the work of the Governor's Task Force on Cancer, the Pennsylvania and Philadelphia Divisions of the American Cancer Society, the Pennsylvania Cancer Coordination Committee, and many other concerned Pennsylvania organizations and individuals.

The Act provided enabling legislation for the Pennsylvania Department of Health to establish nine cancer control priorities, which are as follows:

1) Cancer Registry
2) Cancer screening, detection, and prevention
3) Cancer epidemiology and biostatistical studies
4) Cancer community outreach programs
5) Cancer rehabilitation
6) Communication and planning among cancer institutions
7) Cancer education and information
8) Cancer training
9) Cancer clinical research

The Pennsylvania Cancer Control, Prevention, and Research Act identified the cancer registry as the number one priority for cancer control, mandated reporting of cancer cases, and clearly outlined reporting responsibility. In addition, the law established a Cancer Control, Prevention, and Research Advisory Board to advise the Secretary of Health with respect to cancer control, prevention and research in Pennsylvania and to approve and implement the *Pennsylvania Cancer Plan*. Act 224 was, and continues to be, a key element in the success of the PCR and statewide cancer control activities.

PREFACE

The Act mandated all hospitals and laboratories to report cancer cases to the PCR. The implementation of reporting by acute care hospitals took place in four geographic regions over a period from July 1982 to September 1984 with 1985 being the first full year of statewide reporting. To assure complete statewide incidence statistics, efforts to increase reporting by freestanding laboratories and other non hospital sources began in 1995 and continue to be an ongoing challenge as more patients are diagnosed and treated in these settings.

As a population-based cancer incidence registry, the PCR collects demographic, diagnostic, and first course treatment information on all Pennsylvania residents diagnosed with cancer. All information collected and maintained in the PCR database is strictly confidential. Only summary statistical information is published for general distribution and public knowledge. The Department of Health may permit use of in-depth information for research, subject to careful screening, strict supervision, and only to accomplish approved program objectives.

PCR data are used for cancer research and surveillance activities, as well as epidemiologic and other special studies. State-specific incidence and mortality data are published annually in *Pennsylvania Cancer Incidence and Mortality* that includes the most recent five years of data. Data from this and other statistical reports and publications are available on the Department of Health website at www.health.state.pa.us/stats/.

With a strong and stable history, the PCR is recognized as a state-of-the-art cancer reporting system, an important component in the Department of Health's Cancer Program, and a valuable resource for cancer data. The PCR uses current technology and national data collection standards to continually enhance the completeness, accuracy and timeliness of cancer data. As the volume of PCR incidence data increases over time, the utility of these data for program planning, evaluation, and epidemiologic studies increases as well.

The PCR depends on the support, cooperation, and accurate reporting by each facility and practitioner for the ongoing operation of the statewide cancer registry. Working together, complete, accurate, and timely cancer incidence data will continue to be available to provide answers to our questions, to reduce the burden of cancer in Pennsylvania, and to improve the lives of both present and future patients with cancer.

REPORTING REQUIREMENTS

WHAT IS THE PCR

The Pennsylvania Cancer Registry (PCR) is a population-based cancer incidence registry responsible for the collection of demographic, diagnostic, and first course of treatment information on all cancer patients diagnosed and treated at hospitals, laboratories, and other health care facilities and by health care practitioners in Pennsylvania. These contributing sources required to report to the PCR provide statewide coverage of the population.

WHY REPORT TO THE PCR

The mission of the PCR is to collect and provide complete, accurate, and timely statewide incidence data for determination of cancer rates and trends in the population. To fulfill this mission, the PCR depends on complete ascertainment of cases and use of the data.

1. The Law and Regulations- Statewide collection and dissemination of data on cancer by the Pennsylvania Department of Health is mandated in two state laws and Pennsylvania Department of Health disease-reporting regulations. The state laws include the Pennsylvania Cancer Control, Prevention and Research Act, 35 P.S. §5631 *et seq.,* and the Disease Prevention and Control Law of 1955, 35 P.S. §521.1 *et seq. (PCR Manual Appendix A)* According to these statutes, each designated hospital and laboratory in the Commonwealth shall report all cases of cancer, which are diagnosed and/or treated at the hospital or laboratory. These cases shall be submitted in the format prescribed by the Pennsylvania Cancer Registry. **Regulations mandating reporting cancer cases by hospitals, clinical laboratories, other health care facilities and health care practitioners appear in Section 27.31(b) of 28 Pa.Code Chapter 27 (Communicable and Noncommunicable Diseases).** *(PCR Manual Appendix B)*

2. Cancer Control- The ultimate value of the registry lies not in collection of the data but in the degree to which the data are used for cancer control. The basis for any successful cancer control program is a comprehensive registry system. Registry data provide answers to questions, the means to target limited cancer control resources, and the mechanism to evaluate cancer control activities.

HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA)

HIPAA allows for the reporting of identifiable cancer data to public health entities. Because the PCR falls under the definition of a public health entity, HIPAA regulations permit cases to be reported to the PCR in compliance with Pennsylvania state laws and regulations. Written informed consent from each cancer patient reported to public health entities is not required under HIPAA.

PCR REPORTING SOURCES

Acute care hospitals in Pennsylvania are the source from which most cancer cases are reported to the PCR. As more patients are diagnosed and treated outside the hospital setting, additional sources including freestanding laboratories, other health care facilities and health care practitioners have become essential reporting sources to assure complete statewide data collection of all reportable diagnoses. Non-hospital sources also provide additional treatment information

The PCR depends on all required reporting sources to submit quality data. Through the dedicated efforts of these facilities, the PCR is able to provide accurate information used to establish and enhance cancer control programs, and thus improve the lives of present and future patients with cancer.

Hospitals

Reporting hospitals fall into one of the following categories:

1. Registry Hospitals - The term *registry hospital* refers to hospitals with cancer registries functioning as an integral component of the hospital cancer program. They may or may not be accredited by the American College of Surgeons Commission on Cancer. The cancer registrar or cancer program manager at a registry hospital is delegated the responsibility of reporting to the PCR.

2. Non Registry Hospitals - The term *non registry hospital* refers to hospitals that do not have cancer registries functioning as an integral component of a hospital cancer program. Generally, personnel in the Health Information Management (HIM) Department are delegated the responsibility of reporting to the PCR.

Laboratories

Pathology laboratories fall into one of the following categories:

1. Hospital Laboratories – Reportable cases are identified from pathology reports on hospital inpatients and outpatients as well as from pathology reports on private outpatient (POP) specimens, i.e., specimens submitted for analysis from physician offices. These cases are reported to the PCR by the hospital cancer registrar or Health Information Management (HIM) personnel.

2. Free-Standing Pathology Laboratories - Reporting of cases by free-standing pathology laboratories is performed through electronic transmission of pathology reports. This reporting source identifies histologically confirmed cancer cases diagnosed or treated outside the hospital setting.

Non-Hospital Sources

Non-hospital sources include other health care facilities and health care practitioners. These sources provide information on cases never seen in the hospital setting as well as treatment information for hospital and non-hospital patients.

1. Other Health Care Facilities: Other health care facilities include a) Radiation Centers, b) Medical Oncology Centers, and c) Ambulatory Surgery Centers. Reporting of cases by non-hospital facilities is performed through the submission of copies of medical records via fax, mail or CD.

2. Health Care Practitioners: Reporting by health care practitioners providing diagnostic or therapeutic services for cancer patients identifies cancer cases diagnosed outside the hospitals setting and provides additional information on treatment given to hospital and non-hospital patients.

    - For cancers diagnosed on the basis of tissue specimens, health care practitioners provide information to supplement data from pathology reports reported to the PCR from a pathology laboratory.

    - For cancers diagnosed without tissue specimens, health care practitioners submit copies of medical records via fax, mail, or CD.

PCR REPORTING SOURCES, continued

Data Exchange

The PCR has written agreements to exchange data with other state cancer registries including all contiguous states. This insures a resident of Pennsylvania who was diagnosed and/or treated out-of-state will be included in the PCR database.

DATE OF DIAGNOSIS REPORTABILITY

All reportable cases included on the *PCR List of Reportable Conditions* (See *PCR Manual Appendix C, Reportable Conditions*) are required to be reported to the PCR if they were diagnosed on or after **January 1, 2009**.

REPORTABLE CONDITIONS

PCR List of Reportable Conditions

The *PCR List of Reportable Conditions* is found in the *PCR Manual Appendix C*. This section identifies diagnoses that must be reported to the PCR. Conditions are to be reported if the diagnosis includes the words *malignant, cancer, carcinoma,* and *lymphoma.* Most *leukemias* and *sarcomas* are reportable except when noted as exclusions on the listing. In addition, there are other conditions, which do not include these particular terms but are reportable such as *Wilms tumor, blastoma,* and *carcinoid*. It is therefore very important to refer to the *PCR List of Reportable Conditions* to make sure all reportable conditions are identified.

All primary intracranial and central nervous system (CNS) tumors are reportable. This includes benign, malignant and borderline tumors for the following sites:

- Meninges (C70.0 - C70.9)
- Brain (C71.0 - C71.9)
- Spinal Cord (C72.0)
- Cauda equina (C72.1)
- Cranial nerves (C72.2 - C72.5)
- Other CNS (C72.8, C72.9)
- Pituitary gland (C75.1)
- Craniopharyngeal duct (C75.2)
- Pineal gland (C75.3)

REPORTABLE CODES

ICD-9-CM Codes

Use the following ICD-9-CM codes to identify reportable conditions. To determine if a diagnosis identified from the ICD-9-CM codes is reportable, refer to the reportability guidelines in Part One of this manual.

Some ICD-9-CM codes contain conditions that are not reportable. These records still need to be reviewed and assessed individually to verify whether or not they are reportable to the PCR.

ICD-9-CM Code	Description
140.0 – 209.36	Malignant Neoplasms
209.70-209.79	Secondary neuroendocrine tumors
225.0- 225.9	Benign neoplasm of brain and spinal cord
227.3-227.4	Benign neoplasm of pituitary gland, craniopharyngeal duct (pouch), pineal gland
227.9	Benign neoplasm, endocrine gland, site unspecified
228.02	Hemangioma of intracranial structures
228.1	Lymphangioma, any site
230.0 – 234.9	Carcinoma in situ
236.0	Endometrial stroma, low grade
237.0 – 237.9	Neoplasm of uncertain behavior (borderline) endocrine glands & nervous system
238.4	Polycythemia Vera
238.6- 238.79	Other lymphatic and hematopoietic tissues
239.6-239.89	Neoplasms of unspecified nature
273.2	Other paraproteinemias
273.3	Macroglobulinemia
288.3	Eosinophilia
288.4	Hemophagocytic syndromes
V58.0	Admission for radiotherapy
V58.11	Admission for Chemotherapy
V58.12	Encounter for immunotherapy for neoplastic condition.
V67.1	Radiation therapy follow-up
V67.2	Chemotherapy follow-up

REPORTABLE CASES

Reportable Diagnosis-Solid Tumors

A diagnosis is reportable to the PCR if it is included on the *PCR List of Reportable Conditions* (See *PCR Manual Appendix C, Reportable Conditions*). The following guidelines provide further clarification for the specified conditions:

1. Basal and Squamous Cell Carcinomas- Basal and squamous cell carcinomas are reportable except when primary to the skin, C44.0-C44.9 (see *Exclusions*). Carcinomas originating in mucoepidermoid sites are reportable. These sites include: lip (C00.0-C00.9), anus (C21.0), vulva (C51.0-C51.9), vagina (C52.9), penis (C60.0-C60.9), and scrotum (C63.2). Basal and squamous cell carcinomas originating in the nasal cavity (C30.0) and middle ear (C30.1) are also reportable.

2. Class IV and Class V Cytologies- Cytology results of Class IV or Class V are reportable to the PCR.

   Exception: If the terminology on the cytology report further defines the Class IV and Class V as *suspicious* then the record is not reportable. Report this record only if a positive biopsy or a physician's clinical impression of cancer supports the cytology findings.

3. Intraepithelial Neoplasia- Patients with the following diagnoses of intraepithelial neoplasia are reportable:

   - Vaginal intraepithelial neoplasia 3 (VAIN III)
   - Vulvar intraepithelial neoplasia 3 (VIN III)
   - Anal intraepithelial neoplasia 3 (AIN III)

   See also *PCR Manual Appendix C, Reportable Conditions* and *Exclusions, Intraepithelial Neoplasia.*

4. Non-Malignant Intracranial and Central Nervous System Tumors- All primary intracranial and central nervous system (CNS) tumors are reportable. This includes benign, malignant and borderline tumors for the following sites:

   - Meninges (C70.0 - C70.9)
   - Brain (C71.0 - C71.9)
   - Spinal Cord (C72.0)
   - Cauda equina (C72.1)
   - Cranial nerves (C72.2 - C72.5)
   - Other CNS (C72.8, C72.9)
   - Pituitary gland (C75.1)
   - Craniopharyngeal duct (C75.2)
   - Pineal gland (C75.3)

5. Severe/High Grade Dysplasia of the Colon and/or Esophagus- If your facility considers the terminology of severe dysplasia or high grade dysplasia of the colon and/or esophagus as synonymous with carcinoma in-situ; use the following guidelines for reporting these cases to the PCR:

   a. Obtain a statement from your pathologists outlining the terminology policy of their department. The statements should be separate, one for colon and one for esophagus, because different physicians may be involved in reviewing the statement for each site.

   b. Submit the statement(s) to the appropriate medical staff committee for approval. Registry hospitals will normally submit the statement(s) to the Cancer Committee.

c. Document a policy that states the sites diagnosed with severe dysplasia and/or high grade dysplasia that will be abstracted as carcinoma in-situ based on the pathologists approved statements.

d. Add the policy to your Operations Manual attaching the approved statement(s) from your pathologists.

e. Forward a copy of the policy and statement(s) to the PCR to keep on permanent file.

f. Abstract all colon and/or esophagus cases diagnosed with severe dysplasia and/or high grade dysplasia as carcinoma in-situ according to the statement(s) and policy. In the text for each abstract, document the final pathologic diagnosis along with the statement "in-situ per pathologist".

Reportable Diagnosis- Hematopoietic and Lymphoid Neoplasms

1. Reportability Instructions- For all hematopoietic or lymphoid neoplasms, refer to the *2010 Hematopoietic Database:* http://seer.cancer.gov/tools/heme/index.html

   Note: The *2010 Hematopoietic Database* **must be used** because not all reportable hematopoietic or lymphoid terms are indexed in ICD-O-3.

   Example: Essential Thrombocytosis is coded to ICD-9-CM code 238.71. It is not indexed in ICD-O-3 and is not listed in *Appendix C*. However when checked in the *2010 Hematopoietic Database* it is considered reportable; therefore the case is reportable and must be submitted to the PCR

2. Behavior Code Change from /1 to /3 – The behavior code for hematopoietic neoplasms listed below changed from /1 (borderline or uncertain) to /3 (malignant) and are reportable when diagnosed on or after **January 1, 2010**.

Histologic Terms and Codes with Changes in Case Reportability Effective January 1, 2010	
Name	**ICD-O-3 Code**
Chronic lymphoproliferative disorder of NK-cells	9831/3
T-cell large granular lymphocytic leukemia	9831/3
Langerhans cell histiocytosis, NOS (9751/1)	9751/3
Langerhans cell histiocytosis, unifocal (9752/1)	9751/3
Langerhans cell histiocytosis, multifocal (9753/1)	9751/3
Myelodysplastic/Myeloproliferative neoplasm, unclassifiable	9975/3
Myeloproliferative disease, NOS	9975/3
Myeloproliferative neoplasm, unclassifiable	9975/3

Reportable Situations

A case is reportable to the PCR if it is diagnosed on or after January 1, 2009, is included on the *PCR List of Reportable Conditions* (See *PCR Manual Appendix C, Reportable Conditions*), and meets any of the following criteria:

1. Patients diagnosed or treated in your facility.

   a. Patients Diagnosed At Your Facility - The reportable diagnosis has been made at your facility. This diagnosis can be made on the basis of histology, hematology, cytology, endoscopy or other direct visualization, diagnostic radiology or clinical findings.

      Clinical Diagnosis Only - A "clinical diagnosis only" is a diagnosis based solely on clinical judgment; diagnostic procedures were not performed or did not confirm the diagnosis. Patients diagnosed clinically are reportable to the PCR.

   b. Patients Treated at Your Facility - The PCR requires patients receiving treatment, cancer-directed or non cancer-directed, to be reported provided they have not been previously reported by your facility.

      The PCR recognizes the following definitions of treatment:

      1. Cancer-Directed Treatment - Cancer-directed treatment is tumor directed, and its purpose is to modify, control, remove or destroy primary or metastatic cancer tissue. Physicians administer the therapy (ies) to remove or minimize the size of tumor or to delay the spread of disease.

      2. Non Cancer-Directed Treatment - Non cancer-directed treatments prolong the patient's life, alleviate pain, make the patient comfortable, or prepare the patient for cancer-directed therapy. They are not meant to destroy or control the tumor or delay the spread of disease. Non cancer-directed procedures include diagnostic tests and supportive care (treatments designed to relieve symptoms and minimize the effects of the disease).

         Examples of non cancer-directed treatment include - Incisional biopsy, exploratory procedures with or without biopsies, port-a-catheter insertion, IV access for chemotherapy, pain medications, oxygen, antibiotics for an associated infection, transfusions, intravenous fluids to maintain fluid or nutritional balance, and laser therapy for relieving symptoms.

2. Patients Diagnosed Elsewhere- Patients diagnosed elsewhere and then are seen at your facility for further diagnostic workup or treatment, cancer-directed or non cancer-directed are to be reported.

   Although this may result in multiple records on one patient from different facilities, it enables the PCR to assure complete statewide casefinding and to have the most comprehensive information on each patient. Because the PCR is a population-based registry, every attempt must be made to receive all cases diagnosed within Pennsylvania to provide accurate statistical reports.

3. Residual Tumor-The PCR requires all records in which the pathology report states "no residual tumor" to be reported. The re-excision is considered cancer-directed treatment.

4. Brain and CNS Tumors Identified by Diagnostic Imaging Only- Patients with a brain or CNS tumor identified by diagnostic imaging (CT scans, MRI scans, or ultrasounds/sonography) are reportable even when no other information is available (from biopsy or resection, for example). The behavior for the tumor is coded as /1 (uncertain whether benign or malignant).

5. Additional Reportable Condition – Every reportable diagnosis a patient has must be submitted to the PCR.

EXCLUSIONS

Non-Reportable Diagnosis

The following diagnoses are not reportable to the PCR.

1. Skin Cancers

   a. The following site/histology combinations for skin cancers are not reportable:

8000-8005	Neoplasms malignant, NOS of the skin (C44.0-C44.9)
8010-8046	Epithelial carcinomas of the skin (C44.0-C44.9)
8050-8084	Papillary and squamous cell carcinomas of the skin (C44.0-C44.9)
8090-8110	Basal cell carcinomas of the skin (C44.0-C44.9)

   b. Skin of nose - Basal and squamous cell carcinomas originating in the external nose (C44.3) are not reportable; however, those primary to the nasal cavity (C30.0) such as nostril, nasal septum, and nares are reportable.

   c. Metastasis from non-reportable sites - If the primary site is not reportable but the cancer has metastasized to other sites, the record is still not reportable.

2. Carcinoma-In-Situ of the Cervix (CIS) - The diagnosis carcinoma in situ of the cervix (CIS) is not reportable. Terms indicating in situ include: *noninvasive, preinvasive, intraepithelial,* and *FIGO Stage 0.* A diagnosis of carcinoma in situ with endocervical gland involvement is still considered in situ and is not reportable.

   Note: Diagnoses of invasive carcinoma of the cervix are reportable. A diagnosis of carcinoma in situ of the cervix with microinvasion is considered invasive and is therefore reportable.

3. Intraepithelial Neoplasia- Patients with the following diagnoses of intraepithelial neoplasia are not reportable:

   - Cervical intraepithelial neoplasia (CIN)
   - Prostatic intraepithelial neoplasia (PIN)

   See also *Reportable Cases, Intraepithelial Neoplasia.*

4. Other Precancerous Conditions and Benign Tumors- Patients with precancerous conditions or benign tumors are not reportable. An example of such a diagnosis includes atypical adenoma.

   Exception: Brain and Central Nervous System- All primary intracranial and central nervous system (CNS) tumors are reportable. This includes benign and borderline tumors for the following sites:

   - Meninges (C70.0 - C70.9)
   - Brain (C71.0 - C71.9)
   - Spinal Cord (C72.0)
   - Cauda equina (C72.1)
   - Cranial nerves (C72.2 - C72.5)
   - Other CNS (C72.8, C72.9)
   - Pituitary gland (C75.1)
   - Craniopharyngeal duct (C75.2)
   - Pineal gland (C75.3)

Non-Reportable Situations

A case is not reportable to the PCR if it meets any of the following criteria:

1. Consult Only Records- Patients seen in consultation to provide a second opinion to confirm an established diagnosis or treatment plan are not reportable. Also, if the reporting facility provides services not available at the diagnosing or treatment facility, such as Computerized Tomography (CT) scans or Magnetic Resonance Imaging (MRI) scans, the case is not reportable.

2. Returning Patients- If a patient returns for additional appointments for the same reportable condition, they do not need to be submitted again. However, if the patient begins a treatment regimen as part of their first course of treatment that was not included when the patient was first submitted, that updated information must be submitted. *See Updating information*.

3. Secondary or Subsequent Treatment – If a patient begins secondary or subsequent treatment that is not part of their first course of treatment, that information does not need to be submitted to the PCR.

FIRST COURSE OF TREATMENT

First course of treatment includes all methods of cancer-directed therapy recorded in the treatment plan and administered to the patient before disease progression or recurrence. No therapy is a treatment option (the patient refused therapy, the family/guardian refused therapy, the patient expired before therapy started, or the physician recommended no therapy). Therefore, first course of treatment may be no treatment. All modalities of treatment are included regardless of sequence or degree of completion of any method.

Treatment Plan

A treatment plan describes the cancer-directed treatment intended to modify, control, remove or destroy proliferating cancer cells. All cancer-directed therapies specified in the physician(s) treatment plan are a part of the first course of treatment. A treatment plan may specify one or more modalities of therapy (surgery, radiation, chemotherapy, hormone therapy, immunotherapy, or other therapy). A treatment "regimen" may include combinations of concurrent or adjuvant therapies.

Guidelines for Determining *First Course of Treatment*

First course of treatment includes all cancer-directed therapy planned and administered by the physician(s) during or after the first diagnosis of cancer. Planned treatment may include multiple modes of therapy and may encompass intervals of a year or more.

Time Period Rules for First Course of Treatment for Malignancies except Leukemias (in order of precedence)

1. If there is a documented, planned first course of treatment, first course ends at the completion of this treatment plan, regardless of the duration of the treatment plan.

2. If the patient is treated according to a facility's standards of practice (established protocol), first course ends at the completion of the treatment.

3. If there is no documented treatment plan, established protocol, or management guidelines, use the principle: "initial treatment must begin within four months of the date of initial diagnosis."

4. If the patient refuses all treatment modalities, then changes his/her mind and the treatment is initiated, determine if this is part of first course of treatment.

Special Rules for Leukemias

The first course of definitive treatment is related to the first *remission* as follows:

1. If a remission, complete or partial, is achieved during the first course of therapy for the leukemic process, include:

    - All definitive therapy considered as *remission-inducing* for the first remission.

    - All definitive therapy considered as *remission-maintaining* for the first remission (maintenance chemotherapy or irradiation to the central nervous system).

    - Disregard all treatment administered to the patient after the relapse of the first remission.

2. If no remission is attained during the first course of therapy, submit all treatment attempted to induce the remission.

Watchful Waiting

If a treatment plan is given for symptoms/disease progression after period of *watchful waiting*, this treatment is not considered part of first course. For example, if physician and patient choose a *wait and watch* approach to prostate cancer and the patient becomes symptomatic, consider the symptoms to be an indication the disease has progressed and any further treatment is not part of first course.

Treatment Failure

Treatment failure or disease progression may prompt the physician to stop therapy before the full course has been completed. Any therapy administered after the discontinuation of first course must be considered as secondary or subsequent treatment. An update does not need to be submitted if a patient receives secondary or subsequent treatment

Treatment for Recurrence or Progression

Treatment for recurrence or progression of disease includes all cancer-directed therapies administered after the first course of treatment is complete. If the patient does not respond or if the disease progresses, a physician may stop the first course of treatment before it is complete. Therapy administered after the first course ends is not considered first course of treatment. Treatment for progression of disease should not be submitted as an update.

WHEN IN DOUBT

When in doubt about submitting records to the PCR, ask the following questions:

1. Did your facility diagnose and/or treat the patient for a condition included on the *PCR List of Reportable Conditions? (*See *PCR Manual Appendix C, Reportable Conditions)*

2. Was the condition diagnosed on or after January 1, 2009?

If the answer is yes to both these questions and the record was not previously submitted by your facility, submit the record. If you are in doubt about a particular record, submit the record with a note of explanation or call your PCR Non-Hospital Representative at 1-800-272-1850 or 717-783-2548.

INFORMATION TO REPORT

The PCR collects all data items included in the *PCR Required Data Set,* Appendix E. To meet the requirements for submitting reportable cases to the PCR, the following information must be provided when available:

- Patient demographic information;
- Where patient received diagnosis and first course of treatment
- Initial date patient was seen in your office for diagnosis or first course of treatment
- Date of diagnosis
- Primary site and histology of the reportable condition
- Stage or extent of spread of the cancer at diagnosis
- First course of treatment received or to be given and dates of treatment

A system to track cases reported to the PCR must be established and include the primary site and treatment provided. The purpose of this system is to keep track of the information already submitted and what needs to be submitted when the patient returns.

REPORTING OPTIONS

A. Cancer Registry Database

Health care facilities and practitioners that maintain a cancer registry database may submit reportable cases from the database provided that cases include all PCR-required data items and data items adhere to the standard NAACCR data item codes and definitions adopted for use by the PCR. Abstract Plus software developed by CDC and provided free of charge by the PCR may be used under this option.

The data must be transmitted in an electronic file that conforms to the current NAACCR (North American Association of Central Cancer Registries) record layout for hospital reporting (format available upon request). To assure secure transmittal, the file must be transmitted to the PCR via Web Plus*.

1. Create an export file in the standard NAACCR record layout containing completed cases not previously exported.

2. Create a list of accessioned cases included in the export file.

3. Follow *PCR Web Plus Upload Instructions.* (Web Plus instructions are provided if this option is selected)

4. Add case information to tracking system.

B. Business Agreement With a Hospital-Based Cancer Registry

Health care facilities and practitioners may establish a business agreement with a hospital that has a cancer registry functioning as an integral component of the hospital cancer program. The cancer program does not have to be accredited by the American College of Surgeons Commission on Cancer (ACOS COC) but must follow COC cancer program standards.

The business agreement delegates full responsibility for reporting cases, updates, and meeting all PCR reporting requirements to the hospital cancer registry and provides access to the required information by the hospital cancer registrar. The PCR does not require written confirmation of the business agreement unless reporting requirements are not being met.

Data must be transmitted using the same PCR data item requirements and procedures required for hospital reporting. The hospital must be able to track reported cases.

C. Electronic Medical Record

Health care facilities and practitioners utilizing an electronic medical record may use the following procedure to transmit all reportable cases identified since the last submission. To assure secure transmittal, the file must be sent via Web Plus*.

1. Create a .pdf file of the following reports regardless where the procedure or test was performed:

   - Face sheet
   - Pathology reports
   - Operative reports
   - Radiology reports
   - Any other pertinent reports describing diagnostic findings and treatment
   - Doctors notes
   - Treatment Plans
   - Treatment Summary reports
   - Laboratory results

2. Follow *PCR Web Plus Upload Instructions* (Web Plus instructions are provided if this option is selected)

3. Add case information to tracking system

An alternate method to submitting a .pdf file of cases from an electronic medical record system is to print and fax the reports to the PCR as described below under option D. Paper Medical Record.

D. Paper Medical Record

Health care facilities and practitioners utilizing a paper medical record may use the following procedure to send all reportable cases identified since the last submission.

1. Prepare to fax or mail copies of the following reports from the medical record regardless of where the procedure or test was performed:

- Face sheet
- Pathology reports
- Operative reports
- Radiology reports
- Laboratory results
- Doctors notes
- Treatment Plans
- Treatment Summary reports
- Any other pertinent reports describing diagnostic findings and treatment

2. Complete a PCR Transmittal Form. See *Transmittal Form* section for instructions.

3. Add case information to tracking system.

4. Submit medical record documents and PCR Transmittal Form to the PCR by either:

    - Fax: PCR fax number is 866-531-8238. To assure confidentiality, this fax machine is dedicated for PCR use only.

    - U.S. Mail: Use postage-paid, pre-addressed envelopes supplied by the PCR to mail all shipments and communications. Using these envelopes will assist in having shipments reach the appropriate office within the Department of Health. To order a supply of the envelopes, call the PCR at 1-800-272-1850.

    If PCR mailing envelopes are not available, mail to the following address:

    Bureau of Health Statistics and Research
    ATTN: Cancer Registry
    Pennsylvania Department of Health
    555 Walnut Street – 6th Floor
    Harrisburg, PA 17101

*Web Plus is an Internet-based application developed by the Centers for Disease Control and Prevention (CDC), National Program of Cancer Registries (NPCR). Web Plus has been designed as a highly secure application that can be used to transmit data between reporting facilities and the PCR safely over the public internet. Refer to *PCR Web Plus Upload Instructions* for additional description of security features.

SUBMISSION DATE

Cases must be submitted to the PCR at least monthly, on the last working day of the month. Additional submissions may be made throughout the month.

TRANSMITTAL FORM FOR NEW RECORDS

The PCR Transmittal Form must be included as a coversheet for faxed or mailed submission file. (See *PCR Manual Appendix D, PCR Transmittal Form* for a copy of transmittal form) Facility specific transmittal forms with facility name, PCR four digit identification number and ACOS COS facility identification number are available from the PCR by calling 1-800-272-1850.

Instructions

1. Separate forms - If you have new patients to report as well as updates to report, use a separate form for each type.

2. Date – Enter the date shipment was mailed/faxed.

3. Number of New Records - Enter the number of new records.

4. Total Number of Pages- Enter the number of pages being faxed or mailed.

5. No Records To Report - If a facility has no cancer records to report, a completed transmittal form with zero (0) entered for number of new records must be forwarded to the PCR on the first of the month. In addition, the reason for not submitting any records must be documented on the transmittal form in the space provided.

UPDATING INFORMATION

Importance of Updating Information

The process for updating information insures the most accurate and complete information is available to users of PCR data by enabling reporting sources to provide updated information after a record has been accessioned by the PCR.

What Updates to Submit

1. Submit an update when incorrect or unknown information was initially reported or when more specific/correct information is later available.

   Example: The initial documentation indicated the patient had an unknown primary. But it was later confirmed to be a lung primary. This information must be submitted as an update.

2. Submit an update when additional information becomes available about the initial extent of the disease. This should be limited to information through completion of surgery (ies) in the first course of treatment or within four months of diagnosis in the absence of disease progression whichever is longer.

3. Submit an update for any treatment considered part of the first course of therapy that was not included when the case was initially submitted to the PCR.

   Example: At the time a record was reported to the PCR, the patient did not start Chemotherapy that was planned as part of their First Course of Treatment. The patient later starts the chemotherapy. The chemotherapy information must be submitted to the PCR.

4. Submit an update for name when incorrectly spelled on record and when name is changed due to marital status or other reason. Clearly indicate previous and current name.

When to Submit Updates

Updates should be included with the next monthly submission.

How to Submit Updates

A. Cancer Registry Database

1. Update the information in your database.
2. Print the case from your system
3. Highlight the data items that have been updated
4. Complete a Transmittal form.
5. Fax or mail the updated cases.
6. Add what updated information was submitted to your tracking system.

B. Paper Medical Record (shipments mailed or faxed):

1. Complete a Transmittal form.
2. Fax or mail copies of the patient's demographic information and the report documenting the updated information.
3. Add what updated information was submitted to your tracking system.

C. Electronic Medical Record (shipments uploaded using Web Plus):

1. Create a .pdf file of the patient's demographic information and the report(s) documenting the update treatment.
2. Upload the .pdf file of updates separate from new records.
3. Add what updated information was submitted to your tracking system.

TRANSMITTAL FORM FOR UPDATES

The PCR Transmittal Form must be included as a coversheet for faxed or mailed submission file. (See *PCR Manual Appendix D, PCR Transmittal Form* for a copy of transmittal form) Facility specific transmittal forms with facility name, PCR four digit identification number and ACOS COS facility identification number are available from the PCR by calling 1-800-272-1850.

Instructions

1. Separate forms - If you have new patients to report as well as updates to report, use a separate form for each type.

2. Date – Enter the date shipment was mailed/faxed.

3. Number of Update Records - Enter the number of update records.

4. Total Number of Pages- Enter the number of pages being faxed or mailed.

5. No Records To Report - If a facility has no cancer records to report, a completed transmittal form with zero (0) entered for number of new records must be forwarded to the PCR on the first of the month. In addition, the reason for not submitting any records must be documented on the transmittal form in the space provided.

FACILITY CONTACT PERSON FOR PCR

One person at each reporting facility is designated as the PCR contact person. This person is the primary contact for all correspondence and routine communication with the facility. Each facility designates the PCR contact person such as the office manager, receptionist, correspondence clerk, etc.

To maintain proper communication, inform the PCR of any changes in the contact person at your facility by calling 1-800-272-1850 or (717) 783-2548.

PCR CONTACT NUMBERS

If you have any questions regarding the PCR reporting procedures, contact us at: 1-800-272-1850 or (717) 783-2548.

Fax Number: 866-531-8238

APPENDIX A:
PENNSYLVANIA CANCER CONTROL, PREVENTION AND RESEARCH ACT
(P.L. 1241, No. 224)

Official Advance Copy of Statute Enacted at 1980 Session

No. 1980-224

AN ACT

HB 230

Creating the Pennsylvania Cancer Control, Prevention and Research Advisory Board, providing authorization for the Secretary of Health, upon the recommendation of the Pennsylvania Cancer Control, Prevention and Research Advisory Board, to award grants and contracts for cancer control, prevention and research to associations organized in Pennsylvania and to governmental agencies in Pennsylvania.

The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows:

Section 1. Short title.

This act shall be known and may be cited as the "Pennsylvania Cancer Control, Prevention and Research Act."

Section 2. Definitions.

The following words and phrases when used in this act shall have, unless the context clearly indicates otherwise, the meanings given to them in this section:

"Board." The Pennsylvania Cancer Control, Prevention and Research Advisory Board established by this act.

"Cancer." All malignant neoplasms, regardless of the tissue of origin, including malignant lymphoma and leukemia.

"Secretary." The Secretary of Health of the Commonwealth of Pennsylvania.

Section 3. Pennsylvania Cancer Control, Prevention and Research Advisory Board.

(a) There is hereby created in the Department of Health the "Pennsylvania Cancer Control, Prevention and Research Advisory Board." The board shall consist of 11 members, all of whom shall be Pennsylvania residents, ten of whom the Governor shall appoint by and with the consent of a majority of the Senate. Of the ten appointed, three shall be distinguished scientists and physicians in the field of cancer, one shall be a qualified professional nurse engaged in the practice of oncological nursing, one shall be skilled in health care administration and two with substantial experience in the field of public health, one of whom shall be a professional nurse engaged in the practice of community health nursing, and three consumer members. The Secretary of Health shall be a member of the board.

(b) The terms of the members shall be four years from the respective date of their appointment except that the initial appointments shall be made in such a manner so that four members be appointed for terms of four years, three members be appointed for terms of three years, and three members be appointed for terms of two years.

(c) A chairman shall be appointed by the Governor for a term of four years.

(d) The board shall meet no less than four times annually at the call of the chairman or, in his absence or incapacity at the call of the Secretary of Health. Six members of the board shall constitute a quorum for the purpose of exercising all of the powers of the board. A vote of the majority of the members present shall be sufficient for all actions of the board.

(e) Each board member, except the secretary, shall receive actual travelling expenses and other necessary expenses.

(f) No member of the board shall participate in any discussions and decisions to recommend grants or contracts to any qualified association or to any agency of the Commonwealth or its political subdivisions with which the member is associated as a member of the governing body or as an employee, or with which the member has entered into any contractual arrangement.

Section 4. Responsibilities of the board.

(a) The board shall have the power to prescribe, amend and repeal bylaws governing the manner in which the business of the board is conducted.

(b) The board shall advise the secretary with respect to cancer control, prevention and research in Pennsylvania.

(c) The board shall approve each year a program for cancer control, prevention and research to be known as the "Pennsylvania Cancer Plan."

(d) In order to implement in whole or in part the Pennsylvania Cancer Plan, the board shall recommend to the secretary the awarding of grants and contracts to qualified associations or governmental agencies in order to plan, establish or conduct programs in cancer control or prevention, cancer education and training and cancer clinical research.

(e) Grants and contracts may be recommended for:

(1) Cancer registry.
(2) Cancer screening, detection and prevention.
(3) Cancer epidemiology and biostatistical studies.
(4) Cancer community outreach programs.
(5) Cancer rehabilitation.
(6) Communication and planning among cancer institutions.
(7) Cancer education and information.
(8) Cancer training.
(9) Cancer clinical research.

(f) Consistent with the Pennsylvania Cancer Plan the board shall give its first priority to funding grants and contracts relating to subsection (e)(1), (2) and (3); second priority to funding grants and contracts relating to subsection (e)(4), (5) and (6); third priority to funding grants and contracts relating to subsection (e)(7), (8) and (9).

(g) The following criteria shall be given consideration for recommending grants and contracts for programs:

(1) the relevancy of applicant's proposal to the Pennsylvania Cancer Plan; and

(2) the feasibility of the applicant's proposal.

(h) The board shall recommend to the secretary rules and regulations consistent with law as it may deem necessary for the performance of its duties and the proper administration of this act.

(i) The board shall report annually to the Governor and the General Assembly. The report shall include, but not be limited to, a full description of the grants and contracts funded pursuant to this act, the amount of the grant or contract, an outline of the proposal on which the grant was based, and the results achieved as a result of the grant.

Section 5. Responsibilities of the secretary.

(a) The secretary shall award grants and contracts only from among those recommended by the board to qualified Pennsylvania associations and governmental agencies in order to plan, establish or conduct programs in cancer control and prevention, cancer education and training and cancer research. The secretary may request additional recommendations from the board.

(b) The secretary shall provide such staff, information and other assistance as the secretary may deem necessary for the completion of the board's responsibilities. Such staff shall be responsible to the secretary.

Section 6. Cancer registry.

(a) The Department of Health shall establish a system for the Statewide collection and dissemination of data on cases of cancer by anatomical site, medical and occupational history of patients, stage of disease and other data necessary to effectuate the provisions of this act as determined by the department.

(b) Persons in charge of hospitals and laboratories shall be required by the Department of Health, in accordance with its regulations adopted with the advice of the board to report cases of cancer on forms furnished by the department.

(c) The reports required pursuant to this act shall be confidential and not open to public inspection or dissemination. This shall not restrict the collection and analysis of data by the Department of Health or those with whom the department contracts, subject to strict supervision by the Department of Health to insure that the use of the reports is limited to specific research purposes.

Section 7. Sunset provisions.

With the exception of section 6, this act shall expire on June 30, 1984, unless otherwise extended by an act of the General Assembly.

Section 8. Effective date.
This act shall take effect January 1, 1981.

APPROVED—The 18th day of December, A. D. 1980.

DICK THORNBURGH

PRINTER'S NO. 2130

THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE BILL

No. 1607 Session of 1996

INTRODUCED BY THOMPSON, ROBBINS, PETERSON, ULIANA, DELP, HART, WENGER AND MADIGAN, JUNE 18, 1996

REFERRED TO PUBLIC HEALTH AND WELFARE, JUNE 18, 1996

AN ACT

Amending the act of December 18, 1980 (P.L.1241, No.224), entitled "An act creating the Pennsylvania Cancer Control, Prevention and Research Advisory Board, providing authorization for the Secretary of Health, upon the recommendation of the Pennsylvania Cancer Control, Prevention and Research Advisory Board, to award grants and contracts for cancer control, prevention and research to associations organized in Pennsylvania and to governmental agencies in Pennsylvania," extending the expiration date.

The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows:

Section 1. Section 7 of the act of December 18, 1980 (P.L.1241, No.224), known as the Pennsylvania Cancer Control, Prevention and Research Act, reenacted and amended November 25, 1988 (P.L.1086, No.126) and amended June 30, 1992 (P.L.334, No.67), is amended to read:

Section 7. Sunset provisions.

With the exception of section 6, this act shall expire on June 30, [1996] 2006, unless otherwise extended by an act of the General Assembly.

Section 2. This act shall take effect immediately.

E29L35JS/19960S1607B2130

APPENDIX B:
TITLE 28. HEALTH and SAFETY
PART III. PREVENTION of DISEASES
CHAPTER 27. COMMUNICABLE and NONCOMMUNICABLE DISEASES

Annex A

TITLE 28. HEALTH AND SAFETY
PART III. PREVENTION OF DISEASES
CHAPTER 27. COMMUNICABLE AND NONCOMMUNICABLE DISEASES

Subchapter A. GENERAL PROVISIONS

§ 27.1. Definitions.

The following words and terms, when used in this chapter, have the following meanings, unless the context clearly indicates otherwise:

ACIP--The Advisory Committee on Immunization Practices of the Centers for Disease Control and Prevention, United States Department of Health and Human Services.

Caregiver--The entity or individual responsible for the safe and healthful care or education of a child in a child care group setting.

Case--A person or animal that is determined to have or suspected of having a disease, infection or condition.

Case report form--The form designated by the Department for reporting a case or a carrier.

Central office--Department headquarters located in Harrisburg.

Child--A person under 18 years of age.

Child care group setting--The premises in which care is provided at any one time to four or more children, unrelated to the operator.

Clinical laboratory--A laboratory for which a permit has been issued to operate as a clinical laboratory under the Clinical Laboratory Act (35 P. S. §§ 2151--2165).

Communicable disease--An illness which is capable of being spread to a susceptible host through the direct or indirect transmission of an infectious agent or its toxic product by an infected person, animal or arthropod, or through the inanimate environment.

Communicable period--The time during which an etiologic agent may be transferred directly or indirectly from an infected person to another person, or from an infected animal to a person.

Contact--A person or animal known to have had an association with an infected person or animal which presented an opportunity for acquiring the infection.

District office--One of the district headquarters of the Department located within this Commonwealth.

Health care facility--

(i) A chronic disease, or other type of hospital, a home health care agency, a hospice, a long-term care nursing facility, a cancer treatment center using radiation therapy on an ambulatory basis, an ambulatory surgical facility, a birth center, and an inpatient drug and alcohol treatment facility, regardless of whether the health care facility is operated for profit, nonprofit or by an agency of the Commonwealth or local government.

(ii) The term does not include:
   a) An office used primarily for the private practice of a health care practitioner.
   b) A facility providing treatment solely on the basis of prayer or spiritual means in accordance with the tenets of any church or religious denomination.
   c) A facility conducted by a religious organization for the purpose of providing health care services exclusively to clergy or other persons in a religious profession who are members of a religious denomination.

Health care practitioner--An individual who is authorized to practice some component of the healing arts by a license, permit, certificate or registration issued by a Commonwealth licensing agency or board.

Health care provider--An individual, a trust or estate, a partnership, a corporation (including associations, joint stock companies and insurance companies), the Commonwealth, or a political subdivision, or instrumentality (including a municipal corporation or authority) thereof, that operates a health care facility.

Household contact--A person living in the same residence as a case, including a spouse, child, parent, relation or other person, whether or not related to the case.

Infectious agent--Any organism, such as a virus, bacterium, fungus or parasite, that is capable of being communicated by invasion and multiplication in body tissues and capable of causing disease.

Isolation--The separation for the communicable period of an infected person or animal from other persons or animals, in such a manner as to prevent the direct or indirect transmission of the infectious agent from infected persons or animals to other persons or animals who are susceptible or who may spread the disease to others.

LMRO--Local morbidity reporting office--A district office of the Department or a local health department.

Local health authority--A county or municipal department of health, or board of health of a municipality that does not have a department of health. The term includes a sanitary board.

Local health department--Each county department of health under the Local Health Administration Law (16 P. S. §§ 12001--12028), and each department of health in a municipality approved for a Commonwealth grant to provide local health services under section 25 of the Local Health Administration Law (16 P. S. § 12025).

Local health officer--The person appointed by a local health authority to head the daily administration of duties imposed upon or permitted of local health authorities by State laws and regulations.

Medical record--An account compiled by physicians and other health professionals including a patient's medical history; present illness; findings on physical examination; details of treatment; reports of diagnostic tests; findings and conclusions from special examinations; findings and diagnoses of consultants; diagnoses of the responsible physician; notes on treatment, including medication, surgical operations, radiation, and physical therapy; and progress notes by physicians, nurses and other health professionals.

Modified quarantine--A selected, partial limitation of freedom of movement determined on the basis of differences in susceptibility or danger of disease transmission which is designated to meet particular situations. The term includes the exclusion of children from school and the prohibition, or the restriction, of those exposed to a communicable disease from engaging in particular activities.

Monitoring of contacts--The close supervision of persons and animals exposed to a communicable disease without restricting their movement.

Operator--The legal entity that operates a child care group setting or a person designated by the legal entity to serve as the primary staff person at a child care group setting.

Outbreak--An unusual increase in the number of cases of a disease, infection or condition, whether reportable or not as a single case, above the number of cases that a person required to report would

expect to see in a particular geographic area or among a subset of persons (defined by a specific demographic or other features).

Physician--An individual licensed to practice medicine or osteopathic medicine within this Commonwealth.
Placarding--The posting on a home or other building of a sign or notice warning of the presence of communicable disease within the structure and the danger of infection there from.

Quarantine--

(i) The limitation of freedom of movement of a person or an animal that has been exposed to a communicable disease, for a period of time equal to the longest usual incubation period of the disease, or until judged noninfectious by a physician, in a manner designed to prevent the direct or indirect transmission of the infectious agent from the infected person or animal to other persons or animals.

(ii) The term does not exclude the movement of a person or animal from one location to another when approved by the Department or a local health authority under § 27.67 (relating to the movement of persons and animals subject to isolation or quarantine by action of a local health authority or the Department).

Reportable disease, infection, or condition--A disease, infection, or condition, made reportable by § 27.2 (relating to specific identified reportable diseases, infections and conditions)

SHC--State Health Center--The official headquarters of the Department in a county, other than a district office.

Segregation--The separation for special control or observation of one or more persons or animals from other persons or animals to facilitate the control of a communicable disease.

Sexually transmitted disease--A disease which, except when transmitted perinatally, is transmitted almost exclusively through sexual contact.

Surveillance of disease--The continuing scrutiny of all aspects of occurrence and spread of disease that are pertinent to effective control.

Volunteer--A person who provides services to a school or child care group setting without receiving remuneration.

§ 27.2. Specific identified reportable diseases, infections and conditions.

The diseases, infections and conditions in Subchapter B (relating to the reporting of diseases, infections and conditions) are reportable to the Department or the appropriate local health authority by the persons or entities in the manner and within the time frames set out in this chapter.

§ 27.3. Reporting outbreaks and unusual diseases, infections and conditions.

a) A person required to report under this chapter shall report an outbreak within 24 hours, and in accordance with § 27.4 (relating to reporting cases)
b) A person required to report under this chapter who suspects a public health emergency, shall report an unusual occurrence of a disease, infection or condition not listed as reportable in Subchapter B (relating to reporting of diseases, infections and conditions) or defined as an outbreak, within 24 hours, and in accordance with § 27.4.
c) Any unusual or group expression of illness which the Department designates as a public health emergency shall be reported within 24 hours, and in accordance with § 27.4.

§ 27.4. Reporting cases.

a) Except for reporting by a clinical laboratory, a case is to be reported to the LMRO serving the area in which a case is diagnosed or identified unless another provision of this chapter directs that a particular type of case is to be reported elsewhere. A clinical laboratory shall make reports to the appropriate office of the Department.

b) Upon the Department's implementation of its electronic disease surveillance system for certain types of case reports, persons who make those reports shall do so electronically using an application and reporting format provided by the Department. At least 6 months in advance of requiring a type of case report to be reported electronically, the Department will publish a notice in the *Pennsylvania Bulletin* announcing when electronic reporting is to begin.

c) This section does not prohibit a reporter from making an initial report of a case to the Department or an LMRO by telephone. The reporter will be instructed on how to make a complete case report at the time of the telephone call.

d) Department offices to which this chapter requires specified case reports to be filed are as follows:

    1) Cancer Registry, Division of Health Statistics, Bureau of Health Statistics and Research.
    2) Division of Infectious Disease Epidemiology, Bureau of Epidemiology.
    3) HIV/AIDS Epidemiology Section, Division of Infectious Disease Epidemiology, Bureau of Epidemiology
    4) Division of Maternal and Child Health, Bureau of Family Health.

e) A case shall be reported using the appropriate case report format. Information solicited by the case report form shall be provided by the reporter, irrespective of whether the report is made by submitting the form directly in hard copy or by telecommunication or electronic submission. An appropriate case report form or format may be procured from the office to which the type of case is reportable.

§ 27.5a. Confidentiality of case reports.

Case reports submitted to the Department or to an LMRO are confidential. Neither the reports, nor any information contained in them which identifies or is perceived by the Department or the LMRO as capable of being used to identify a person named in a report, will be disclosed to any person who is not an authorized employe or agent of the Department or the LMRO, and who has a legitimate purpose to access case information, except for any of the following reasons:

1) When disclosure is necessary to carry out a purpose of the act, as determined by the Department or LMRO, and disclosure would not violate another act or regulation.
2) When disclosure is made for a research purpose for which access to the information has been granted by the Department or an LMRO. Access shall be granted only when disclosure would not violate another act or regulation. The research shall be subject to strict supervision by the LMRO to ensure that the use of information disclosed is limited to the specific research purpose and will not involve the further disclosure of information which identifies or is perceived as being able to be used to identify a person named in a report.

§ 27.6. Disciplinary consequences for violating reporting responsibilities

a) Failure of a clinical laboratory to comply with the reporting provisions of this chapter may result in restrictions being placed upon or revocation of the laboratory's permit to operate as a clinical laboratory, as provided for in the Clinical Laboratory Act (35 P. S. §§ 2151--2165) unless failure to report is due to circumstances beyond the control of the clinical laboratory.
b) Failure of a Department licensed health care facility to comply with the reporting provisions of this chapter may result in restrictions being placed upon or revocation of the health care facility's license, as provided for in the Health Care Facilities Act (35 P. S. §§ 448.101--448.904b)
c) Failure of a health care practitioner to comply with the reporting provisions of this chapter may result in referral of that matter to the appropriate licensure board for disciplinary action.
d) Failure of a child care group setting to comply with the reporting provisions of this chapter may result in referral of that matter to the appropriate licensing agency for appropriate action.

§ 27.7. Cooperation between clinical laboratories and persons who order laboratory tests.

To facilitate the reporting of cases by clinical laboratories, the following is required:

1) When a clinical laboratory is requested to conduct a test which, depending upon the results, would impose a reporting duty upon the clinical laboratory, the clinical laboratory shall provide to the person who orders the testing, a form that solicits all information which is required for completion of the applicable case report form.
2) A person who orders testing subject to paragraph (1) shall, at the time of ordering the test, provide the clinical laboratory with the information solicited by the form which that person either possesses or may readily obtain.

§27.8. Criminal penalties for violating the act or this chapter.

a) A person who violates any provision of the act or this chapter shall, for each offense, upon conviction thereof in a summary proceeding before a district justice in the county wherein the offense was committed, be sentenced to pay a fine of not less than $25 and not more than $300, together with costs, and in default of payment of the fine and costs, shall be imprisoned in the county jail for a period not to exceed 30 days.
b) A person afflicted with communicable tuberculosis, ordered to be quarantined or isolated in an institution, who leaves without consent of the medical director of the institution, is guilty of a misdemeanor, and upon conviction thereof, shall be sentenced to pay a fine of not less than $100 nor more than $500, or undergo imprisonment for not less than 30 days nor more than 6 months, or both.
c) Prosecutions may be instituted by the Department, by a local health authority, or by any person having knowledge of a violation of the act or this chapter.

Subchapter B. REPORTING OF DISEASES, INFECTIONS AND CONDITIONS GENERAL

§ 27.21. Reporting of AIDS cases by physicians and hospitals.

A physician or a hospital is required to report a case of AIDS within 5 workdays after it is identified to the local health department if the case resides within the jurisdiction of that local health department. In all other cases, the physician or hospital shall report the case to the HIV/AIDS Epidemiology Section, Division of Infectious Disease Epidemiology, Bureau of Epidemiology.

§ 27.21a. Reporting of cases by health care practitioners and health care facilities.

a) Except as set forth in this section or as otherwise set forth in this chapter, a health care practitioner or health care facility is required to report a case of a disease, infection or condition in subsection (b) as specified in § 27.4 (relating to reporting cases), if the health care practitioner or health care facility treats or examines a person who is suffering from, or who the health care practitioner suspects, because of symptoms or the appearance of the individual, of having a reportable disease, infection or condition:

    1) A health care practitioner or health care facility is not required to report a case if that health care practitioner or health care facility has reported the case previously.
    2) A health care practitioner or health care facility is not required to report a case of influenza unless the disease is confirmed by laboratory evidence of the causative agent.
    3) A health care practitioner or health care facility is not required to report a case of chlamydia trachomatis infection unless the disease is confirmed by laboratory evidence of the infectious agent.
    4) A health care practitioner or health care facility is not required to report a case of cancer unless the health care practitioner or health care facility provides screening, therapy or diagnostic services to cancer patients.
    5) Only physicians and hospitals are required to report cases of AIDS.

b) The following diseases, infections and conditions in humans are reportable by health care practitioners and health care facilities within the specified time periods and as otherwise required by this chapter:

1) The following diseases, infections and conditions are reportable within 24 hours after being identified by symptoms, appearance or diagnosis:

Animal bite.
Anthrax.
Arboviruses.
Botulism.
Cholera.
Diphtheria.
Enterohemorrhagic E. coli.
Food poisoning outbreak.
Haemophilus influenzae invasive disease.
Hantavirus pulmonary syndrome.
Hemorrhagic fever.
Lead poisoning.
Legionellosis.
Measles (rubeola).
Meningococcal invasive disease.
Plague.
Poliomyelitis.
Rabies.
Smallpox
Typhoid fever

2) The following diseases, infections and conditions are reportable within 5 work days after being identified by symptoms, appearance or diagnosis:

AIDS
Amebiasis.
Brucellosis.
Campylobacteriosis.
Cancer.
Chancroid.
Chickenpox (varicella)
Chlamydia trachomatis infections.
Creutzfeldt-Jakob Disease.
Cryptosporidiosis.
Encephalitis.
Giardiasis.
Gonococcal infections.
Granuloma inguinale.
Guillain-Barre syndrome.
Hepatitis, viral, acute & chronic cases.
Histoplasmosis.
Influenza.
Leprosy (Hansen's disease).
Leptospirosis.
Listeriosis.
Lyme disease.
Lymphogranuloma venereum.
Malaria.
Maple syrup urine disease (MSUD) in children under 5 years of age.
Meningitis (All types not caused by invasive Haemophilus influenza or Neisseria meningitis).
Mumps.
Pertussis (whooping cough).
Phenylketonuria (PKU) in children under 5 years of age.
Primary congenital hypothyroidism in children under 5 years of age.
Psittacosis (ornithosis).
Rickettsial diseases.
Rubella (German measles) and congenital rubella syndrome.
Salmonellosis.
Shigellosis.
Sickle cell hemoglobinopathies in children under 5 years of age.
Staphylococcus aureus, Vancomycin-resistant (or intermediate) invasive disease.
Streptococcal invasive disease (group A).
Streptococcus pneumoniae, drug-resistant invasive disease.
Syphilis (all stages).
Tetanus.
Toxic shock syndrome.
Toxoplasmosis.
Trichinosis.
Tuberculosis, suspected or confirmed active disease (all sites).
Tularemia.

c) A school nurse shall report to the LMRO any unusual increase in the number of absentees among school children. A caregiver at a child care group setting shall report to the LMRO any unusual increase in the number of absentees among children attending the child care group setting.
d) A health care facility or health care practitioner providing screening, diagnostic or therapeutic services to patients with respect to cancer shall also report cases of cancer as specified in § 27.31 (relating to reporting cases of cancer).

§ 27.22. Reporting of cases by clinical laboratories.

a) A person who is in charge of a clinical laboratory in which a laboratory examination of a specimen derived from a human body yields evidence significant from a public health standpoint of the presence of a disease, infection or condition listed in subsection (b) shall promptly report the findings, no later than the next work day after the close of business on the day on which the examination was completed, except as otherwise noted in this chapter.

b) The diseases, infections and conditions to be reported include the following:

Amebiasis.
Anthrax.
An unusual cluster of isolates.
Arboviruses
Botulism--all forms.
Brucellosis.
Campylobacteriosis.
Cancer.
Chancroid.
Chickenpox (varicella).
Chlamydia trachomatis infections.
Cholera.
Creutzfeldt-Jakob disease.
Cryptosporidiosis.
Diphtheria infections.
Enterohemorrhagic E. coli 0157 infections, or infections caused by other sub-types producing shiga-like toxin.
Giardiasis.
Gonococcal infections.
Granuloma inguinale.
Haemophilus influenzae infections--invasive from sterile sites.
Hantavirus.
Hepatitis, viral, acute and chronic cases.
Histoplasmosis.
Influenza.
Lead poisoning.
Legionellosis.
Leprosy (Hansen's disease).
Leptospirosis.
Listeriosis.
Lyme disease.
Lymphogranuloma venereum.
Malaria.
Maple syrup urine disease (MSUD) in children under 5 years of age.
Measles (rubeola).
Meningococcal infections--invasive from sterile sites.
Mumps.
Pertussis.
Phenylketonuria (PKU) in children under 5 years of age.
Primary congenital hypothyroidism in children under 5 years of age.
Plague.
Poliomyelitis.
Psittacosis (ornithosis).
Rabies.
Respiratory syncytial virus.
Rickettsial infections.
Rubella.
Salmonella.
Shigella.
Sickle cell hemoglobinopathies in children under 5 years of age.
Staphylococcus Aureus Vancomycin-resistant (or intermediate) invasive disease.
Streptococcus pneumoniae, drug-resistant invasive disease.
Syphilis.
Tetanus.
Toxoplasmosis.
Trichinosis.
Tuberculosis, confirmation of positive smears or cultures, including results of drug susceptibility testing.
Tularemia.
Typhoid.

c) The report shall include the following:

1) The name, age, address and telephone number of the person from whom the specimen was obtained.
2) The date the specimen was collected.
3) The source of the specimen (such as, serum, stool, CSF, wound).
4) The name of the test or examination performed and the date it was performed.
5) The results of the test.
6) The range of normal values for the specific test performed.
7) The name, address, and telephone number of the physician for whom the examination or test was performed.
8) Other information requested in case reports or formats specified by the Department.

d) The report shall be submitted by the person in charge of a laboratory, in either a hard copy format or an electronic transmission format specified by the Department.
e) Reports made on paper shall be made to the LMRO where the case is diagnosed or identified. Reports made electronically shall be submitted to the Division of Infectious Disease Epidemiology, Bureau of Epidemiology. Reports of maple syrup urine disease, phenylketonuria, primary congenital hypothyroidism, sickle cell hemoglobinopathies, cancer and lead poisoning shall be reported to the location specifically designated in this subchapter. See §§ 27.30, 27.31 and 27.34 (relating to reporting cases of certain diseases in the newborn child; reporting cases of cancer; and reporting cases of lead poisoning).
f) A clinical laboratory shall submit isolates of salmonella and shigella to the Department's Bureau of laboratories for serotyping within 5 work days of isolation.
g) A clinical laboratory shall submit isolates of Neisseria meningitidis obtained from a normally sterile site to the Department's Bureau of Laboratories for serogrouping within 5 work days of isolation.
h) A clinical laboratory shall send isolates of enterohemorrhagic E. coli to the Department's Bureau of Laboratories for appropriate further testing within 5 work days of isolation.
i) A clinical laboratory shall send isolates of Haemophilus influenzae obtained from a normally sterile site to the Department's Bureau of Laboratories for serotyping within 5 work days of isolation.
j) The Department, upon publication of a notice in the *Pennsylvania Bulletin*, may authorize changes in the requirements for submission of isolates based upon medical or public health developments when the departure is determined by the Department to be necessary to protect the health of the people of this Commonwealth. The change will not remain in effect for more than 90 days after publication unless the Board acts to affirm the change within that 90-day period.

§ 27.23. Reporting of cases by persons other than health care practitioners, health care facilities, veterinarians or laboratories.

Except with respect to reporting cancer, individuals in charge of the following types of group facilities identifying a disease, infection or condition listed in § 27.21a (relating to reporting of cases by health care practitioners and health care facilities) by symptom, appearance or diagnosis shall make a report within the time frames required in § 27.21a.

1) Institutions maintaining dormitories and living rooms.
2) Orphanages.
3) Child care group settings.

§ 27.24. (Reserved).

§ 27.24a. Reporting of cases by veterinarians.

A veterinarian is required to report a case, as specified in § 27.4 (relating to reporting cases), only if the veterinarian treats or examines an animal which the veterinarian suspects of having a disease set forth in § 27.35(a) (relating to reporting cases of disease in animals).

§§ 27.25--27.28. (Reserved).

§ 27.29. Reporting for special research projects.

A person in charge of a hospital or other institution for the treatment of disease shall, upon request of the Department, make reports of a disease or condition for which the Board has approved a specific study to enable the Department to determine and employ the most efficient and practical means to protect and to promote the health of the people by the prevention and control of the disease or condition. The reports shall be made on forms prescribed by the Department and shall be transmitted to the Department or to local health authorities as directed by the Department.

DISEASES AND CONDITIONS REQUIRING SPECIAL REPORTING

§ 27.30. Reporting cases of certain diseases in the newborn child.

Reports of maple syrup urine disease, phenylketonuria, primary congenital hypothyroidism and sickle cell hemoglobinopathies shall be made to the Division of Maternal and Child Health, Bureau of Family Health, as specified in Chapter 28 (relating to metabolic diseases of the newborn) and those provisions of § 27.4 (relating to reporting cases) consistent with Chapter 28 and this section.

§ 27.31. Reporting cases of cancer.

a) A hospital, clinical laboratory, or other health care facility providing screening, diagnostic or therapeutic services for cancer to cancer patients shall report each case of cancer to the Department in a format prescribed by the Cancer Registry, Bureau of Health Statistics and Research, within 180 days of the patient's discharge, if an inpatient or, if an outpatient, within 180 days following diagnosis or initiation of treatment.
b) A health care practitioner providing screening, diagnostic or therapeutic services to cancer patients for cancer shall report each cancer case to the Department in a format prescribed by the Cancer Registry, Bureau of Health Statistics and Research, within 5 work days of diagnosis. Cases directly referred to or previously admitted to a hospital or other health care facility providing screening, diagnostic or therapeutic services to cancer patients in this Commonwealth, and reported by those facilities, are exceptions and do not need to be reported by the health care practitioner.
c) The Department or its authorized representative shall be afforded physical access to all records of physicians and surgeons, hospitals, outpatient clinics, nursing homes and all other facilities, individuals or agencies providing 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 cancer patient.
d) Reports submitted under this section are confidential and may not be open to public inspection or dissemination. Information for specific research purposes may be released in accordance with procedures established by the Department with the advice of the Pennsylvania Cancer Control, Prevention and Research Advisory Board.
e) Case reports of cancer shall be sent to the Cancer Registry, Division of Health Statistics, Bureau of Health Statistics and Research, unless otherwise directed by the Department.

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APPENDIX C:
REPORTABLE CONDITIONS

This *List of Reportable Conditions* provides documentation of all conditions reportable to the Pennsylvania Cancer Registry (PCR). It is structured alphabetically by the main histologic term. Qualifiers and/or adjectives associated with the main term are included only if needed to specify when the condition is reportable. The abbreviation "NOS" means "Not Otherwise Specified."

Note: **Not all hematopoietic or lymphoid neoplasms are included in *Appendix C.* If a hematopoietic or lymphoid neoplasm is not listed in *Appendix C,* the *2010 Hematopoietic Database* must be reviewed to determine if the hematopoietic or lymphoid case is reportable.**

The Hematopoietic database can be downloaded from the following website:

http://seer.cancer.gov/tools/heme.

Example: Essential Thrombocytosis is not listed in Appendix C. However when checked in the *2010 Hematopoietic Database* it is considered reportable; therefore the case is reportable and must be submitted to the PCR.

Determining Reportable Conditions Using Histologic Terms

Conditions are to be reported if the diagnosis includes the terms cancer, carcinoma, malignant**,** and lymphoma**.** Most leukemias and sarcomas are reportable except as noted as exclusions on the listing. Other reportable conditions not containing these terms (i.e., refractory anemia, stromal endometriosis, Ewing tumor, carcinofibroma) are also included in this listing.

All primary intracranial and central nervous system (CNS) tumors are reportable. This includes benign, malignant and borderline tumors for the following sites:

Reportable Intracranial and Central Nervous System (CNS) Primary Sites Effective January 1, 2004	
Meninges (C70.0 - C70.9)	Other CNS (C72.8, C72.9)
Brain (C71.0 - C71.9)	Pituitary gland (C75.1)
Spinal Cord (C72.0)	Craniopharyngeal duct (C75.2)
Cauda equina (C72.1)	Pineal gland (C75.3)
Cranial nerves (C72.2 - C72.5)	

Determining Reportable Conditions Using *ICD-O* Behavior Codes

1. Behavior /2 or /3- All records with a behavior code of /2 (in situ) or /3 (malignant) in the *International Classification of Diseases for Oncology, Second Edition* (ICD-O-2) or *Third Edition* (ICD-O-3) are reportable.

   Exception: Pilocytic/Juvenile astrocytoma (code 9421/3 in ICD-O-2 and 9421/1 in ICD-O-3) is reportable and must be coded with a behavior of /3 (malignant). Adding this change in the alphabetic and tabular listing of the ICD-O-3 code book will assist in identifying them as reportable conditions and assigning the appropriate code.

   Note: If a pathologist verifies a /0 (benign) or /1 (uncertain whether benign or malignant) behavior code term in ICD-O as /2 (in situ) or /3 (malignant), these records are reportable.

2. Primary Intracranial And Central Nervous System Tumors - Effective with cases diagnosed on or after **January 1, 2004** primary intracranial and central nervous system tumors with a behavior code of **/0** or **/1** (benign and borderline or "non-malignant") are reportable regardless of histologic type for the sites listed above under *Intracranial and Central Nervous System Sites* are reportable.

3. Hematopoietic and lymphoid neoplasms- The following table lists hematopoietic conditions that are reportable beginning with cases diagnosed on or after **January 1, 2010**. Based on changes to the hematopoietic and lymphoid neoplasm rules, the behavior of the following diseases has changed from borderline or uncertain (/1) to malignant (/3).

Histologic Terms and Codes with Changes in Case Reportability Effective January 1, 2010	
Name	**ICD-O-3 Code**
Chronic lymphoproliferative disorder of NK-cells	9831/3
T-cell large granular lymphocytic leukemia	9831/3
Langerhans cell histiocytosis, NOS (9751/1)	9751/3
Langerhans cell histiocytosis, unifocal (9752/1)	9751/3
Langerhans cell histiocytosis, multifocal (9753/1)	9751/3
Myelodysplastic/Myeloproliferative neoplasm, unclassifiable	9975/3
Myeloproliferative disease, NOS	9975/3
Myeloproliferative neoplasm, unclassifiable	9975/3

Exclusions

Conditions are not to be reported to the PCR if the diagnosis includes:

- Cancers primary to the skin (C44.0-C44.9) with the following histologies:
  - Neoplasms, malignant, NOS of the skin
  - Epithelial carcinomas of the skin
  - Squamous cell carcinomas (SCC) of the skin
  - Basal cell carcinomas (BCC) of the skin

  Note: These lesions are reportable for squamous and basal cell cancers originating in mucoepidermoid sites: lip, anus, vulva, vagina, penis or scrotum (*ICD-O* codes C00.0-C00.9, C21.0, C51.0-C51.9, C52.9, C60.0-60.9 & C63.2). Basal and squamous cell carcinomas originating in the nasal cavity and middle ear are also reportable ((*ICD-O* codes C30.0 and C30.1)

- Cervical intraepithelial neoplasia (CIN)

- Prostatic intraepithelial neoplasia (PIN)

Legend for List of Reportable Conditions

Use this legend to interpret special designations used on the following list of currently reportable conditions:

- **Bold Print**- Benign and borderline behaviors of these conditions are only reportable if the primary site is listed under *Intracranial and Central Nervous System Sites* on page 1 of *Appendix C*.

- * (Single asterisk) - Not reportable if primary to skin as specified under Exclusions.

REPORTABLE CONDITIONS

Adamantinoma (long bones, malignant, tibial only)
Adenoacanthoma
Adenocarcinofibroma
Adenocarcinoma
Adenofibroma (malignant endometrioid only)
Adenoma
Adenosarcoma
AIN III (anal intraepithelial neoplasia, grade III)
Ameloblastoma (malignant only)
Androblastoma (malignant only)
Anemia, refractory
Angioendotheliomatosis
Angiolipoma
Angiomyosarcoma
Angiosarcoma
Argentaffinoma (malignant only)
Arrhenoblastoma (malignant only)
Astroblastoma
Astrocytoma
Astroglioma
Blastoma
Cancer*
Carcinoid (exclude tumor of appendix, strumal, argentaffin tumor NOS, enterochromaffin-like cell NOS, and tubular)
Carcinofibroma
Carcinoma*
Carcinomatosis*
Carcinosarcoma
CASTLE (Carcinoma showing thymus-like element)
Chloroma
Cholangiocarcinoma
Chondroblastoma (malignant only)
Chondrosarcoma
Chordoma
Choriocarcinoma
Chorioepithelioma
Chorionepithelioma
Class IV cytology
Class V cytology
Comedocarcinoma
CPNET (central primitive neuroectodermal, NOS)
Craniopharyngioma
Cylindroma (exclude eccrine dermal, and skin)
Cyst, dermoid (with malignant transformation only or with secondary tumor, **NOS**)
Cystadenocarcinofibroma
Cystadenocarcinoma
Cystadenofibroma (malignant endometrioid only)
Cystosarcoma phyllodes (malignant only)
Cytopenia, refractory with multilineage dysplasia
Dermatofibrosarcoma
Diktyoma (malignant only)
DIN III (ductal intraepithelial neoplasia, grade III)
Disease - include only:
- alpha heavy chain
- Bowen*
- Di Guglielmo
- Franklin
- gamma heavy chain
- Heavy chain NOS
- Hodgkin
- immunoproliferative (NOS and small intestinal only)
- Letterer-Siwe
- mast cell, systemic tissue
- Mu heavy chain
- Myeloproliferative, chronic
- Paget* (exclude of bone)
- Sezary

Disorder, myeloproliferative, chronic
Disorder, primary cutaneous CD30+ T-cell lymphoproliferative
Dysgerminoma
Ectomesenchymoma
Endometriosis, stromal
Enteroglucagonoma (malignant only)
Ependymoblastoma
Ependymoma
Epithelioma* (NOS, basal cell, malignant, and squamous cell only)
Erythremia (acute and chronic only)
Erythroleukemia
Erythroplasia, Queyrat*
Esthesioneuroblastoma

See page 2 of *Appendix C* for legend of special designations.

REPORTABLE CONDITIONS

Esthesioneurocytoma
Esthesioneuroepithelioma
Fibrochondrosarcoma
Fibrodentinosarcoma
Fibroepithelioma, of Pinkus type or NOS*/
Fibrolipoma
Fibroliposarcoma
Fibroma, NOS
Fibromyxosarcoma
Fibro-odontosarcoma
Fibrosarcoma
Fibroxanthoma (malignant only)
Gangliocytoma
Ganglioglioma (anaplastic)
Ganglioneuroblastoma
Ganglioneuroma
Gastrinoma (malignant only)
Gemistocytoma
Germinoma
GIST-Gastrointestinal stromal tumor (malignant only)
Glioblastoma
Gliofibroma
Glioma, astrocytic, malignant, NOS, **chordoid, subependymal**
Gliomatosis cerebri
Gliosarcoma
Glomangiosarcoma
Glucagonoma (malignant only)
Granuloma (Hodgkin only)
Hemangioblastoma
Hemangioendothelioma
Hemangioma
Hemangiopericytoma
Hemangiosarcoma
Hepatoblastoma
Hepatocarcinoma
Hepatocholangiocarcinoma
Hepatoma (exclude benign)
Hidradenocarcinoma
Hidradenoma (malignant only)
Histiocytoma (malignant fibrous only)
Histiocytosis (malignant, and acute progressive X only)
Histiocytosis, Langerhans cell, disseminated or generalized
Hutchinson melanotic freckle (melanoma in only)
Hypernephroma
Immunocytoma
Insulinoma (malignant only)
LCIS, NOS (lobular carcinoma in situ)
Leiomyoma (NOS)
Leiomyomatosis (NOS)
Leiomyosarcoma
Lentigo maligna
Leukemia (exclude granular lymphocytic)
Linitis plastica
Lipoma (atypical or NOS)
Liposarcoma (exclude well differentiated liposarcoma, superficial)
LN III, LN 3 (of breast also called lobular neoplasia, grade 3 only)
Lymphangioendothelioma (malignant only)
Lymphangiosarcoma
Lymphoblastoma
Lymphoepithelioma*
Lymphoma
Lymphosarcoma
Macroglobulinemia, Waldenstrom
Malignancy*
Malignant*
Mastocytoma (malignant only)
Mastocytosis (malignant only)
Medulloblastoma
Medulloepithelioma
Medullomyoblastoma
Melanocytosis, diffuse
Melanocytoma, meningeal
Melanoma (exclude juvenile)
Melanomatosis, meningeal
Melanosis (precancerous only)
Meningioma (anaplastic, papillary, rhabdoid)
Meningiomatosis (NOS)
Mesenchymoma (malignant only)
Mesonephroma (exclude benign)
Mesothelioma (exclude benign and cystic)
Metaplasia, agnogenic myeloid
Microglioma
MPNST, NOS (malignant peripheral nerve sheath tumor)
Mycosis fungoides

See page 2 of *Appendix C* for legend of special designations.

REPORTABLE CONDITIONS

Myelofibrosis (acute, chronic idiopathic, with myeloid metaplasia or as a result of myeloproliferative disease only)
Myeloma
Myelomatosis
Myelosclerosis (megakaryocytic, acute, malignant or with myeloid metaplasia)
Myelosis
Myoblastoma (malignant granular cell only)
Myoepithelioma (malignant only)
Myosarcoma
Myosis, stromal NOS or endolymphatic stromal
Myxoliposarcoma
Myxosarcoma
Neoplasia, ductal intraepithelial, grade 3 (of breast – also called DIN III)
Neoplasia, intratubular germ cell
Neoplasia, lobular, grade 3 only of breast (also called LN III, LN 3)
Neoplasia, squamous intraepithelial, grade 3 (of anus, vulva and vagina only- also called, AIN III, VIN III and VAIN III)
Neoplasm
Nephroblastoma
Nephroma (exclude mesoblastic)
Neurilemmoma
Neurilemmosarcoma
Neurinomatosis
Neuroblastoma
Neurocytoma (olfactory)
Neuroepithelioma
Neurofibroma
Neurofibromatosis (NOS)
Neurofibrosarcoma
Neuroma (NOS)
Neurosarcoma
Neurothekeoma
Nevus (malignant blue only)
Odontosarcoma
Oligoastrocytoma, mixed
Oligodendroblastoma
Oligodendroglioma
Orchioblastoma
Osteochondrosarcoma
Osteoclastoma (malignant only)
Osteofibrosarcoma
Osteosarcoma
Pancreatoblastoma
Panmyelosis, acute only
Papilloma
Papulosis, lymphomatoid
Paraganglioma
Paragranuloma, Hodgkin
Perineural MPNST
Perineurioma (malignant)
Pheochromoblastoma
Pheochromocytoma (malignant only)
Pilomatrixoma* (malignant only)
Pineoblastoma
Pinealoma (NOS)
Pineocytoma
Plasmacytoma
PNET (primitive neuroectodermal tumor)
Pneumoblastoma
Polycythemia (proliferative, rubra vera, or vera)
Polyembryoma
Polyposis (malignant lymphomatous only)
Porocarcinoma
Poroma, eccrine (malignant only)
PPNET (peripheral primitive neuroectodermal tumor)
Preleukemia
Prolactinoma
Pseudomyxoma peritonei
Queyrat erythroplasia*
Reticuloendotheliosis
Reticulosarcoma
Reticulosis (histiocytic medullary, malignant, pagetoid and polymorphic only)
Retinoblastoma
Rhabdomyoma (NOS)
Rhabdomyosarcoma
Rhabdosarcoma
Sarcoma (exclude well differentiated liposarcoma, superficial)
Sarcomatosis (meningeal only)
Schwannoma (malignant only)
Seminoma
SETTLE (spindle epithelial tumor with thymus-like element)
Somatostatinoma (malignant only)
Spermatocytoma
Spiradenoma (malignant only)

See page 2 of *Appendix C* for legend of special designations.

REPORTABLE CONDITIONS

Spongioblastoma (polar or malignant **only)**
Spongioneuroblastoma
Stromatosis, endometrial
Struma (malignant ovarii and Wuchernde
Langhans only)
Subependymoma
Sympathicoblastoma
Syndrome,
5q deletion with myelodysplastic syndrome
Hypereosinophilic
Myelodysplastic
NOS
with 5q deletion syndrome
therapy-related, NOS
therapy-related, alkylating agent related
therapy-related, epipodophyllotoxin related
Preleukemic
Sezary
Synovioma (NOS and malignant only)
Syringoma chondroid, (malignant only)
Teratoblastoma, malignant
Teratocarcinoma
Teratoma
Thecoma (malignant only)
Thrombocythemia (essential, essential hemorrhagic, idiopathic, or idiopathic hemorrhagic)
Thymoma (malignant or type C only)
Tumor - include only:
adenocarcinoid
adrenal cortical (malignant only)
alpha cell (malignant only)
Askin
atypical lipomatous
Bednar
beta cell (malignant only)
Brenner (malignant only)
Burkitt
carcinoid, NOS (except of appendix)
carcinoid (malignant only)
cells
desmoplastic small round cell
dysembryoplastic neuroepithelial
embolus*
endodermal sinus
epithelial*
Ewing
Tumor - include only cont:
fibrous, solitary (malignant)
follicular dendritic cell
fusiform cell type* (malignant only)
G cell (malignant only)
gastrin cell (malignant only)
gastrointestinal stromal (malignant only)
germ cell
giant cell (malignant only)
glomus (malignant only)
granular cell
granulosa cell (malignant or sarcomatoid only)
Grawitz
interstitial cell (malignant only)
intravascular bronchial alveolar
Klatskin
Krukenberg
Leydig cell (malignant only)
lipomatous, atypical
malignant* (any type)
mast cell (malignant only)
Merkel cell
mesenchymal (malignant only)
mesodermal, mixed
metastatic*
mixed pineal
mixed salivary gland type (malignant only)
mucocarcinoid
Mullerian mixed
neuroectodermal (exclude melanotic)
nonencapsulating sclerosing
odontogenic (malignant only)
olfactory, neurogenic
Pancoast
peripheral neuroectodermal or peripheral primitive neuroectodermal, NOS
peripheral nerve sheath (malignant)
phyllodes (malignant only)
pineal parenchymal of intermediate differentiation
Pinkus***/**
plasma cell
polyvesicular vitelline
primitive neuroectodermal

See page 2 of *Appendix C* for legend of special designations.

REPORTABLE CONDITIONS

Tumor - include only cont:
- rhabdoid, NOS
- rhabdoid/teratoid, atypical
- round cell, desmoplastic, small
- Schminke
- secondary*
- Sertoli-Leydig cell (poorly differentiated, with heterologous elements, sarcomatoid, malignant)
- sinus, endodermal
- small cell type* (malignant only)
- **smooth muscle (NOS)**
- **soft tissue**
- spindle cell type* (malignant only)
- spindle epithelial with thymus-like element or thymus-like differentiation
- steroid cell (malignant only)
- sweat gland (malignant only)
- teratoid/rhabdoid, atypical
- transitional pineal
- triton, malignant
- trophoblastic, epithelioid
- vitelline, polyvesicular
- Wilm
- yolk sac

Ulcer, rodent*
VAIN III (vaginal intraepithelial neoplasia, grade 3)
VIN III (vulvar intraepithelial neoplasia, grade 3)
Vipoma (malignant only)
Xanthoastrocytoma, pleomorphic

See page 2 of *Appendix C* for legend of special designations.

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APPENDIX D:
PCR TRANSMITTAL FORM

pennsylvania
DEPARTMENT OF HEALTH

PENNSYLVANIA CANCER REGISTRY
TRANSMITTAL FORM

FACILITY NAME:	Dr Pennsylvania
CITY:	Anytown
PCR IDENTIFICATION NUMBER:	9999
ACOS COC IDENTIFICATION NUMBER:	0006239999
DATE SUBMITTED:	_____
NUMBER OF UPDATE RECORDS:	_____
NUMBER OF NEW RECORDS:	_____
TOTAL NUMBER OF PAGES:	_____

Complete a separate form for Update and New Records. If zero records are indicated, document reason below:

_____

_____

_____

_____

_____

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APPENDIX E:
REQUIRED DATA SET
FOR REPORTING FACILITIES

Required Data Set for Reporting Facilities

PCR Required Data Item	Field length	NAACCR Item #
Name--Last	40	2230
Name--Suffix	3	2270
Name--First	40	2240
Name--Middle	40	2250
Name--Maiden	40	2390
Name--Alias	40	2280
Addr at DX--No & Street	60	2330
Addr at DX--Supplementl	60	2335
Addr at DX--City	50	70
Addr at DX--State	2	80
Addr at DX--Postal Code	9	100
County at DX	3	90
Addr Current--No & Street	60	2350
Addr Current—Supplementl	60	2355
Addr Current—City	50	1810
Addr Current—State	2	1820
Addr Current--Postal Code	9	1830
Age at Diagnosis	3	230
Date of Birth	8	240
Date of Birth Flag	2	241
Birthplace	3	250
Social Security Number	9	2320
Sex	1	220
Spanish/Hispanic Origin	1	190
Race 1	2	160
Race 2	2	161
Race 3	2	162
Race 4	2	163
Race 5	2	164
Primary Payer at DX	2	630
Text--Usual Occupation	100	310
Text--Usual Industry	100	320
Medical Record Number	11	2300
Sequence Number--Hospital	2	560
Class of Case	2	610
Type of Reporting Source	1	500
Date of 1st Contact	8	580
Date of 1st Contact Flag	2	581
Date of Inpatient Adm	8	590
Date of Inpt Adm Flag	2	591

Required Data Set for Reporting Facilities

PCR Required Data Item	Field length	NAACCR Item #
Date of Inpatient Disch	8	600
Date of Inpt Disch Flag	2	601
Institution Referred From	10	2410
Physician—Follow-up	8	2470
Date of Diagnosis	8	390
Date of Diagnosis Flag	2	391
Primary Site	4	400
Laterality	1	410
Histology (92-00) ICD-O-2	4	420
Behavior (92-00) ICD-O-2	1	430
Histologic Type ICD-O-3	4	522
Behavior Code ICD-O-3	1	523
Grade	1	440
Grade Path Value	1	441
Grade Path System	1	449
ICD-O-3 Conversion Flag	1	2116
Diagnostic Confirmation	1	490
CS Tumor Size	3	2800
CS Extension	3	2810
CS Tumor Size/Ext Eval	1	2820
CS Lymph Nodes	3	2830
CS Lymph Nodes Eval	1	2840
Regional Nodes Examined	2	830
Regional Nodes Positive	2	820
Lymph-vascular Invasion	1	1182
CS Mets at DX	2	2850
CS Mets Eval	1	2860
CS Mets at DX-Bone	1	2851
CS Mets at DX-Brain	1	2852
CS Mets at DX-Liver	1	2853
CS Mets at DX-Lung	1	2854
CS Site-Specific Factor 1	3	2880
CS Site-Specific Factor 2	3	2890
CS Site-Specific Factor 3	3	2900
CS Site-Specific Factor 4	3	2910
CS Site-Specific Factor 5	3	2920
CS Site-Specific Factor 6	3	2930
CS Site-Specific Factor 7	3	2861
CS Site-Specific Factor 8	3	2862
CS Site-Specific Factor 9	3	2863

Required Data Set for Reporting Facilities

PCR Required Data Item	Field length	NAACCR Item #
CS Site-Specific Factor 10	3	2864
CS Site-Specific Factor 11	3	2865
CS Site-Specific Factor 12	3	2866
CS Site-Specific Factor 13	3	2867
CS Site-Specific Factor 14	3	2868
CS Site-Specific Factor 15	3	2869
CS Site-Specific Factor 16	3	2870
CS Site-Specific Factor 17	3	2871
CS Site-Specific Factor 18	3	2872
CS Site-Specific Factor 19	3	2873
CS Site-Specific Factor 20	3	2874
CS Site-Specific Factor 21	3	2875
CS Site-Specific Factor 22	3	2876
CS Site-Specific Factor 23	3	2877
CS Site-Specific Factor 24	3	2878
CS Site-Specific Factor 25	3	2879
SEER Summary Stage 1977	1	760
SEER Summary Stage 2000	1	759
RX Summ--Surg Prim Site	2	1290
RX Date--Surgery	8	1200
RX Date--Surgery Flag	2	1201
RX Summ--Scope Reg LN Sur	1	1292
RX Summ--Surg Oth Reg/Dis	1	1294
Reason for No Surgery	1	1340
Rad--Regional RX Modality	2	1570
RX Date--Radiation	8	1210
RX Date--Radiation Flag	2	1211
RX Summ-Surg/Rad Seq	1	1380
RX Date--Chemo	8	1220
RX Date--Chemo Flag	2	1221
RX Summ--Chemo	2	1390
RX Date--Hormone	8	1230
RX Date--Hormone Flag	2	1231
RX Summ--Hormone	2	1400
RX Date--BRM	8	1240
RX Date--BRM Flag	2	1241
RX Summ--BRM	2	1410
RX Summ-Systemic Sur Seq	1	1639
RX Summ--Transplnt/Endocr	2	3250
RX Summ--Other	1	1420

Required Data Set for Reporting Facilities

PCR Required Data Item	Field length	NAACCR Item #
RX Date--Other	8	1250
RX Date--Other Flag	2	1251
Date of 1st Crs RX--COC	8	1270
Date of 1st Crs RX Flag	2	1271
RX Summ--Treatment Status	1	1285
Date of Last Contact	8	1750
Date of Last Contact Flag	2	1751
Vital Status	1	1760
Reporting Facility	10	540
Abstracted By	3	570
Text--DX Proc-PE	1000	2520
Text--DX Proc-X-ray/Scan	1000	2530
Text--DX Proc-Scopes	1000	2540
Text--DX Proc-Lab Tests	1000	2550
Text--DX Proc-Op	1000	2560
Text--DX Proc-Path	1000	2570
Text--Primary Site Title	100	2580
Text--Histology Title	100	2590
Text--Staging	1000	2600
RX Text--Surgery	1000	2610
RX Text--Radiation (Beam)	1000	2620
RX Text--Radiation (Other)	1000	2630
RX Text--Chemo	1000	2640
RX Text--Hormone	1000	2650
RX Text--BRM	1000	2660
RX Text--Other	1000	2670
Text--Remarks	1000	2680
Text--Place of Diagnosis	60	2690

Required Data Set for Reporting Facilities

System Codes

PCR Required Data Item	Field length	NAACCR Item #
Record Type	1	10
Registry Type	1	30
FIN Coding System	1	35
NAACCR Record Version	3	50
Race Coding Sys--Current	1	170
Site Coding Sys--Current	1	450
Morph Coding Sys--Current	1	470
RX Coding System--Current	2	1460
First Course Calc Method	1	1500
ICD Revision Number	1	1920
Date Case Completed	8	2090
Date Case Last Changed	8	2100
Date Case Report Exported	8	2110
COC Coding Sys--Current	2	2140
Vendor Name	10	2170
CS Version Input Original	6	2935
CS Version Derived	6	2936
CS Version Input Current	6	2937