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Series IV: Cancer Case Ascertainment

Table of Contents

Introduction ............................................................................................................................................ IV–5
Reportable Cases .................................................................................................................................... IV–7
The Case Ascertainment Process .......................................................................................................... IV–13
Guidelines for Data Acceptance/Rejection ........................................................................................... IV–23
Guidelines for Evaluating Interfield Inconsistencies and Discrepancies .............................................. IV–25
References ............................................................................................................................................ IV–26
Appendix A: U.S. Census Bureau Residency Rules ............................................................................. IV–28
Appendix B: Examples of Central Cancer Registry Procedures for Obtaining Cancer Cases From Physician Offices ........................................................................................................ IV–31
Appendix C: Example of Central Cancer Registry Pathology Laboratory Nonelectronic Reporting Procedures ........................................................................................................ IV–39
Appendix D: NAACCR-Recommended Central Cancer Registry Reportable List ............................... IV–42
Appendix E: Example of ICD-CM Code List ....................................................................................... IV–48
Appendix F: Examples of Central Cancer Registry State Laws ............................................................ IV–49
Appendix G: Example of Central Cancer Registry Nonreportable List ............................................... IV–61
Appendix H: Academic Letter Interpreting HIPAA; Legal Letter Interpreting HIPAA ....................... IV–65
Appendix I: Example of Central Cancer Registry Casefinding Procedures and List ......................... IV–72
Appendix J: Example of Central Cancer Registry Procedures for Evaluating Inconsistencies Between Data Items; Example of Discrepancy Letter ......................................................... IV–75
Appendix K: Example of Central Cancer Registry Case Acceptance Policies .................................. IV–77
Introduction

Background

Central cancer registries in the United States and in some parts of Canada are legislatively charged with the systematic and standardized collection of information for individuals diagnosed with cancer. This information can be utilized to achieve goals related to cancer surveillance, research, and control. Success in achieving these goals is dependent on the availability of timely, complete, and high-quality data. To this end, central cancer registry staff dedicate time, effort, and strategic planning to ensure and enhance factors related to improved timeliness, completeness, and quality of the collected cancer data.

In the last decade, significant progress has been made in the development of standards to support the operations of cancer registries. Key standard-setting bodies include: the American College of Surgeons (ACoS); Canadian Council of Cancer Registries (CCCR); International Agency for Research on Cancer (IARC); North American Association of Central Cancer Registries (NAACCR); National Program of Cancer Registries (NPCR); and the Surveillance, Epidemiology and End Results Program (SEER).

As a North American standard-setting body for central population-based cancer registries, NAACCR recognizes the existence of several issues that impact registries’ ability to achieve uniformity in cancer registration. This document reflects the results of a consensus exercise to examine best practices in registries in the United States and Canada. This work has been conducted under the auspices of the NAACCR Registry Operations Committee as part of the NAACCR initiative to document best practices for registries.

Current Issues

Across North America, central cancer registries experience several challenges in accomplishing their goals. These challenges include:

- **Standards and Procedures**: Despite improvements in standards and procedural definitions, it is clear that inconsistencies exist among ACoS, CCCR, IARC, NAACCR, NPCR, and SEER. Focused efforts are required to align standards and procedures. In addition, there is a need for adequate, well-defined documentation of standards and procedures once they are developed. This can be particularly challenging for newer registries that must establish documentation in cancer-reporting processes for the first time.

- **Staffing**: A majority of the staffing issues are related to high turnover, inexperience, and lack of trained, qualified coding and abstracting staff. Many factors contribute to this, including inadequate salaries, inadequate human resource planning, and difficulty in recruiting professionals to geographically isolated environments in states and provinces with small populations.

- **Funding**: Lack of adequate funding plagues many registries, greatly affecting their ability to achieve complete coverage of their specified geographic area. Inadequate funding is a significant challenge to registries that are attempting to take advantage of information technology to enhance their registry operations.
Overall, these challenges can contribute to gaps in consistent registry operations and adversely affect case ascertainment and case completeness.

**Scope of Work**

The scope of this manual is to document guidelines for various steps in the case ascertainment process. Where possible, recommendations are made to resolve existing differences between ACoS, CCCR, IARC, NAACCR, NPCR, and SEER. In addition, business model diagrams are included as visual aids to assist in understanding the process of cancer case ascertainment as well as to facilitate the identification of procedural steps that are potentially problematic to the overall process. Best practice procedures for several steps within the case ascertainment process are included in the appendices. These best practice procedures were developed with input from a number of central cancer registries throughout North America.
Reportable Cases

Requirements for Cancer Case Reporting

Cancer case reporting requirements in the United States and Canada are broadly defined by legislation. State, provincial, and territorial legislation share common components but vary in certain details depending on local needs and resources. Legislation usually requires the reporting of all in situ or malignant neoplasms (behavior code 2 or 3) that occur within the geographic region covered by the cancer registry. Most laws do not require the reporting of basal and squamous cell carcinomas of the skin or in situ carcinoma of the cervix uteri, although some central registries still record these cases for historical purposes or for special studies.

Additionally, some legislation authorizes central registries to collect data on benign tumors, either because of the significance of the disease (e.g., benign brain tumors) or for research purposes (e.g., trophoblastic tumors). Although these additional cases may not be reportable to the funding agency (SEER or NPCR), they typically are of special interest to certain epidemiology and research groups.

Guidelines for Case Ascertainment

The scope of this work is limited to establishing case ascertainment guidelines for the following:

- Reference date
- Residency
- Multiple primary cancers
- Analytic/Nonanalytic Case (Class of Case)
- Ambiguous terms
- Diagnostic confirmation.

Reference Date. The reference date is defined as the effective diagnosis date on which cancer registration starts in a specified, at-risk population by the central cancer registry, or in a specific facility (e.g., the hospital cancer registry). It is not the date the registry is organized or the date work actually is performed at the registry. All reportable cases diagnosed on or after the reference date must be included in the registry database. Central registries also should maintain information on the date for which a specific cancer was deemed reportable or not reportable, because not all cancers have been reportable for the same length of time. One example is borderline malignancy of the ovary. This condition was not reportable under the International Classification of Diseases for Oncology [Version 1] (ICD-O-1) (behavior code 1), but was reportable under the ICD-O-2 (behavior code 3), and is not reportable under the ICD-O-3 (behavior code 1). Funding agencies may determine the reference date of importance to them. However, many state registries have their own reference date, which often is prior to that of the funding agency. For example, the Connecticut Cancer Registry has been registering cancer since 1935, but only cases diagnosed since 1973 are reported to SEER. Typically, most central registries report information on the basis of a calendar year.
NAACCR recommends that central cancer registries include all reportable cancer cases in their databases, even if their date of diagnosis is prior to the registry's reference date. Allowing case ascertainment to be unrestricted by registry reference date permits central registries to: (1) decrease the number of cases identified through death certificates only (DCO); (2) enhance the possibility for record linkage; and (3) increase the potential for identifying missing cases. However, one of the major drawbacks of registry cases that predate the reference date is the increased workload for central cancer registry staff—this may require resources that currently are not available.

**Residency.** Cancer registries must have rules for determining residency of all reportable cases, particularly when the residency status of a cancer case is not apparent. This often is the case for part-year residents (e.g., seasonal or part-time residents, institutionalized persons, homeless persons, military personnel, and students). SEER, ACoS, and NAACCR agree that when determining the residency of a cancer case, U.S. central cancer registries should use the same rules established by the U.S. Census Bureau in enumerating the population. Using the same rules as the Census is particularly important because the Census is the source for the population at risk, the denominator for calculating cancer incidence and mortality rates.

The U.S. Census 2000 rules for defining residence follow the concept of “usual residence,” which is defined as the place where the person lives and sleeps most of the time. Central registries in the United States are encouraged to use the Census definitions of residency. A suggested central cancer registry adaptation of the Census rules for residency for a variety of types of living arrangements is included in Appendix A.

Canada is in the process of developing national residency rules. These rules are in draft form and will be made available at a later date.

NAACCR recommends that central cancer registries participate in data exchange agreements with surrounding states, provinces, and territories. This involves the collection of nonresident cases in their catchment area from other states or provinces. Benefits of case sharing include enhanced case reporting, because failure to report nonresident cases would result in underreporting incident cases for some states. Additionally, such an exchange could facilitate the death clearance process and other record linkages. Central registries need to explore whether legislative requirements allow for this exchange.

**Multiple Primary Cancers.** Knowing which set of rules was used for multiple primary cancer determination is important when comparing cancer incidence rates among central registries. However, the three main standard setters (SEER, IARC, and ACoS) as well as the CCCR have different rules. IARC rules result in the registration of fewer tumors. IARC rules only allow for one tumor per site, per person, per lifetime with the same histology (except for Kaposi’s sarcoma and mesothelioma). SEER rules take into consideration site differences, histological type differences, and whether or not tumors are simultaneous. ACoS and SEER rules are very similar, except that ACoS rules do not allow for the reporting of an invasive cancer as another primary incident cancer if the cancer was preceded by an in situ cancer and the doctor considers the invasive cancer to be a recurrence. ACoS counts this as one primary tumor, while SEER counts this as two primary tumors. Based on the CCCR multiple primary registration rules, it is likely that Canada reports a slightly lower number of cases than other countries using the other standards. These rules are further explained in Berg (1996) for IARC, SEER Code Manual for SEER, Registry Operations and Data Standards (ROADS) for ACoS, and the CCR Data Dictionary for CCCR. SEER multiple primary determination rules are the de facto standard in the United States, but IARC is used internationally. Compared to the SEER rules, IARC rules define fewer primaries. Recent changes in the ACoS rules have made them more comparable to SEER. These changes, located in the ACoS ROADS Volume II publication, currently are in draft form.
All cancer registries should follow one of these standards in deciding how to report multiple primary tumors. Central registries in the United States are encouraged to follow SEER rules. Registries in Canada are encouraged to follow CCCR rules, although Ontario currently follows IARC rules. Accredited hospital cancer registries in the United States currently follow ACoS rules. Reporting facilities should report cases to central cancer registries according to rules provided by their central cancer registry. Differences in the ACoS and SEER rules affect the case counts among reporting facilities and central cancer registries.

NAACCR recommends that central cancer registries become fully aware of the differences in the multiple primary rules and their potential impact.

**Analytic/Nonanalytic Cases (Class of Case).** Class of Case is a U.S. hospital registry data item used to designate a case as analytic or nonanalytic. An analytic case is diagnosed and/or treated (first course of therapy or all treatment) at a reporting facility, and a nonanalytic case is one that is diagnosed and received the first course of therapy or all treatment before admission to the reporting facility. Cases are divided into 9 classes, with classes 0–2 considered analytic, and classes 3–5, 8, and 9 nonanalytic (please see NAACCR Standards for Cancer Registries, Volume II, p 152, 6th Edition for a description of each class). Central cancer registries use this information to qualify the data received from the reporting institution. Hospital registrars are not required by ACoS to report cancer cases diagnosed and/or treated in a staff physician’s office (class 6), although these cases still are reportable to central cancer registries. Because physician reporting is not routinely implemented by central registries, there is the possibility of missed cases resulting in a lower documented incidence of cancer. This may particularly affect cancers that are more often diagnosed and treated at physicians’ offices such as melanomas, prostate, leukemia, lymphoma, and possibly breast cancers.

Canadian registries do not currently utilize this data item.

Many barriers exist in identifying and registering the cases diagnosed and/or treated in physician offices, not the least of which are resources and health care policies. As the number of patients seen exclusively in physician offices continues to increase, developing a cost-effective strategy to obtain information on cancer cases seen in these settings becomes increasingly important. NAACCR recommends the following actions that central cancer registries can take to obtain these cases:

- Implement pathology laboratory reporting procedures
- Write letters to certain specialists to retrieve data on specific cancers most likely to be seen in nonhospital settings (e.g., urologists, dermatologists)
- Work closely with physician groups to rally their support.

Many central cancer registries are actively developing and implementing procedures to obtain such cases. Procedures and sample letters sent to physicians from central registries in Nebraska, New Jersey, and Utah are included in Appendix B.

Pathology laboratories and registries should discuss various options for identifying which events or reports should be submitted to the requesting central cancer registry, and specifically how they will be submitted. Some registries review all pathology laboratory events or reports so that they can be screened for reportable diagnoses or conditions. In other situations, the registry and the pathology laboratory may need to define specific criteria (such as laboratory tests, diagnoses, or conditions) to be used by the laboratory to select the events or reports to be submitted. An example of nonelectronic laboratory reporting procedures and criteria from the Illinois State Cancer Registry is included in Appendix C.
Please refer to the NAACCR Standards for Cancer Registries, Volume II, Chapter 6, for procedures for electronic laboratory reporting.¹

Not all pathology laboratory reports are coded at the time of their submission, leaving the central cancer registry with the responsibility to code some of the data from the reports. The following coding strategies can be employed by the central cancer registry:

- Text search string (manual or computer review)
- Encoding software (SNOMED, ICD-O-2, and ICD-O-3)
- Provide pathology laboratories with current ICD-O codes.

**Ambiguous Terms.** There are times when the pathologist or physician is not clear about a cancer diagnosis. As a result, the terminology used in the pathology report and throughout the patient’s chart is sometimes vague, ambiguous, or imprecise. Some terms are more indicative of a cancer diagnosis than others. ACoS and SEER have a list of ambiguous terms used by medical practitioners that are considered diagnostic of cancer, and a list of terms that, when used, are not considered diagnostic of cancer. Canada has adopted the SEER list of ambiguous terms as the Canadian standard. Slight differences exist between the ACoS and SEER lists. NAACCR recommends that all central registries use the SEER list for determining ambiguous terms because it is the most inclusive. Lists 1 and 2 present the SEER ambiguous terms.

**List 1.** Ambiguous terms considered diagnostic of cancer (case is reportable).

- Compatible with
- Consistent with
- Most likely
- Probable
- Suspect
- Suspicious*
- Apparent(ly)
- Appears
- Comparable
- Favors
- Malignant appearing
- Presumed
- Typical of

*Exception: If the cytology is reported as “suspicious” and no positive biopsy or physician’s clinical impression supports the cytology findings, do not consider as a diagnosis of cancer.

**List 2.** Ambiguous terms NOT considered diagnostic of cancer (case is not reportable).

- Equivocal
- Possible
- Questionable
- Suggests
• Worrisome
• Cannot be ruled out
• Potentially malignant

The College of American Pathologists (CAP) is working to clarify pathology terms. Recent proposed changes from CAP include all SEER ambiguous terms that constitute a cancer diagnosis as well as SEER ambiguous terms that do not constitute a cancer diagnosis. In addition, the term “rule out” now is included on CAP’s list of terms not considered diagnostic of cancer. CAP’s document currently is in draft form.

**Diagnostic Confirmation.** Diagnostic confirmation refers to the best method used by both central and hospital cancer registries to document and establish how the cancer was diagnosed.\(^4\) The different types of diagnostic confirmation are referred to in the NAACCR Standards for Cancer Registries, Volume II, and include histology, cytology, nonspecified microscopic confirmation, laboratory, radiography, direct visualization, and clinical diagnosis only (without any laboratory or x-ray).\(^7\) Although a positive histology is the most definitive diagnostic confirmation of cancer,\(^4\) some cancers are only confirmed clinically for a variety of reasons (e.g., patients with severe comorbid conditions or advanced age at diagnosis).

Regardless of the diagnostic methods used, NAACCR recommends that every reportable cancer case be registered. Additionally, NAACCR agrees with the recommendation by SEER, NPCR, CCCR, and ACoS that the most definitive diagnostic confirmation for any cancer case be reported.

**Development of a Reportable List**

ACoS, NPCR, CCCR, and SEER have developed lists of reportable cancer cases that over recent years have achieved greater consensus. Cancer registries often adopt one of these lists, depending on their own local needs as well as their relationships with these organizations. However, given the different focus of each organization, these lists continue to vary from each other to a certain degree. This represents a potential problem when combining data from various central registries in NAACCR’s yearly calls for data.

To resolve these issues and prevent further gaps in data acquisition and quality, NAACCR recommends the following:

• Central cancer registries should provide a list of applicable disease classification codes (i.e., ICD-9 or ICD-10) assigned to reportable conditions to reporting institutions for their use in casefinding and case reporting.

• The list should be based on requirements and considerations of individual area legislation, funding sources, and accreditation agencies.

• Facilities should abstract data based on the most inclusive list. If the reporting facility’s internal reportable list is different from that of the central cancer registry, the reporting facility should submit only cases reportable to the central registry.

• Reporting laws/statutes/rules should be sufficiently flexible to accommodate revisions of a list of reportable cases as cancer reporting requirements change.
Examples of a recommended reportable list, ICD-CM code list, and various state laws (from New York, New Jersey, Pennsylvania, and Utah) can be found in Appendixes D, E, and F.

**Development of a Nonreportable List**

In addition to the development of a reportable list, NAACCR recommends that central cancer registries also develop a list of nonreportable diagnoses that includes common tumors that are not reportable (e.g., precancerous conditions and certain skin cancers). Several cancer registries already have gone through the process of creating nonreportable lists and share them with their reporting facilities. Examples can be found in Appendix G.
The Case Ascertainment Process

Ultimately, the central cancer registry is responsible for accurate and complete reporting of cancer incidence for its assigned geographic region. This, however, requires collaboration with reporting sources, because most central cancer registries use secondary procedures to ascertain cases. In the United States, reporting of cancers to central cancer registries is mandated by law or regulations specified by state public health authorities. Central cancer registries can be located within state health departments, universities, or other related agencies. In Canada, there also is a legislative mandate to support the reporting of cancers to central registries in most territories and provinces.

Reporting Sources

Figure 1 summarizes the sources for cancer case ascertainment. Reporting sources include health care facilities and non-health care facilities. Several types of health care facilities are involved in this endeavor and include hospitals, pathology laboratories, health care practitioner offices, and freestanding nonhospital medical facilities. Hospitals include inpatient and outpatient types of facilities. For the purpose of cancer data reporting, hospital cancer resources are comprised of oncology services, hospital pathology laboratories, diagnostic imaging, surgery logs, and coded indices (i.e., disease index and billing index). Possible types of outpatient hospital facilities include day surgery, cancer centers, and cancer clinics. Hospices, radiation centers, surgery centers, and chemotherapy centers are types of freestanding nonhospital medical facilities. Hospices may alternatively be a part of an inpatient hospital facility. Non-health care facilities include the Bureau of Vital Statistics; Office of the Medical Examiner (city, county, state); health insurance plans; and other state cancer registries.

In Canada and the United States, hospitals are the most important source of data for cancer reporting. For most central cancer registries, more than 75 percent of all cancer cases reported to the central cancer registry are from hospital records. Within the hospital, the majority of cases are found from laboratory sources such as anatomical pathology, cytology, bone marrow, hematology, and autopsy results. Medical records and disease indices for both inpatients and outpatients also are major sources for casefinding. A considerable, yet smaller, number of cases can be found from documents of medical imaging—both diagnostic and interventional. Radiation oncology, medical oncology, surgery lists, and specialty services (e.g., dental/ocular) are other hospital sources for finding cancer cases.

Within surgery centers or freestanding clinics, casefinding sources include pathology, billing or disease indices, patient logs, and medical imaging. A few cases are reported from laboratories only, the most common of which are leukemias diagnosed by blood smear and lung cancers diagnosed by cytology only. Although not as common, prostate cancer cases may have only a clinical diagnosis based on prostate-specific antigen (PSA) levels. A PSA-only diagnosis usually is due to the patient’s age or an underlying medical condition that prevents further diagnostic tests. Some cancers have large numbers of cases diagnosed in physicians’ offices or by private medical practitioners. These include prostate, melanoma, and bladder cancers. Because of logistical difficulties associated with ensuring proper case reporting from nonhospital facilities, the incidence of specific cancers is believed to be underreported when case reporting is limited to hospitals only.

Types of information available from non-health care facilities include updates on addresses and vital status, as well as supplementary demographic information (e.g., race and ethnicity). Typically, only a few cases are found through these sources alone. For cases initially reported by one of these sources, the
Figure 1. Facilities – cancer data sources (overview).
The central cancer registry should find supporting documentation from other medical resources. Central cancer registries need to be aware of all sources in their reporting area where a cancer case could be identified.

**Cancer Casefinding**

The way that cancer cases are found and reported (casefinding) may vary depending on the reporting source. Three types of casefinding—active, passive, and a combination of both active and passive—are described below:

- **Active** casefinding occurs when the central registry staff assume the responsibility for the review of pathology laboratory reports, disease indices, patient logs, and so on.

- **Passive** casefinding occurs when the central registry staff rely on someone else to identify and report the cases. Also, it may occur when the central registry staff rely on someone else to provide lists of reportable cases from pathology laboratories, disease indices, or patient logs.

- **Combination** of the two casefinding methods is used by many central registries. For example, many pathology laboratories send copies of all pathology reports to the central registry, whose staff review the reports for reportable cases.

Regardless of the type of casefinding used, central registry staff must document the type of reporting source for each tumor (e.g., pathology laboratory, hospital, physician).

**Cancer Reporting Sources**

As described above, central cancer registries obtain most of their cases from hospitals, but the remaining cases can be found in a variety of health care and non-health care facilities. To ensure case completeness, NAACCR recommends that all central cancer registries obtain 100 percent of all hospital cancer cases. Efforts to obtain nonhospital cases should start with outpatient facilities, move to medical providers, and finally progress to non-health care facilities such as the Bureau of Vital Statistics. Table 1 summarizes NAACCR’s recommended list of cancer reporting and casefinding sources, based on the number of expected cases from each source. The order presented in Table 1 is intended to maximize case completeness. Priorities may vary depending on local needs.

**Table 1.** NAACCR’s recommended cancer case reporting sources and casefinding sources.

<table>
<thead>
<tr>
<th>Reporting Sources:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitals (inpatient)</td>
</tr>
<tr>
<td>1. Major casefinding</td>
</tr>
<tr>
<td>i. Laboratories</td>
</tr>
<tr>
<td>- Pathology</td>
</tr>
<tr>
<td>- Cytology</td>
</tr>
<tr>
<td>- Bone marrow</td>
</tr>
<tr>
<td>- Serum laboratories</td>
</tr>
<tr>
<td>- Autopsy</td>
</tr>
<tr>
<td>ii. Medical records—disease indices</td>
</tr>
<tr>
<td>2. Minor (backup) casefinding</td>
</tr>
<tr>
<td>i. Medical imaging</td>
</tr>
<tr>
<td>- Diagnostic</td>
</tr>
</tbody>
</table>
Additionally, NAACCR recommends that central cancer registries monitor the number of reported cases versus the number of expected cases from each facility throughout the year and identify interventions that can enhance case completeness when case reporting levels fall below expectations.

Tables 2 and 3 display two examples of the distribution of the best “type of reporting source,” based on interpretations of the prescribed hierarchy (NAACCR item #500, SEER Standard). The data are from the Illinois State Cancer Registry (an NPCR registry) and the Utah Cancer Registry (a SEER registry), both NAACCR certified at the gold level in 2001. SEER has developed a hierarchy of sources that reflects the expected completeness and accuracy of the reports from the various types of sources. Hospital reports are considered to be the most comprehensive, and DCO reports are the least comprehensive. Although the nonhospital sources vary considerably in their relative contributions to these two registries, without these reports (Illinois and Utah), both states would miss approximately 10 percent of their cases.

Table 2. Illinois State Cancer Registry (registry size = ~55,000 cases [invasive + bladder in situ only] per year).

<table>
<thead>
<tr>
<th>Source</th>
<th>Percent Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>90</td>
</tr>
<tr>
<td>Out-of-state data exchange</td>
<td>5</td>
</tr>
<tr>
<td>Death certificate only</td>
<td>2</td>
</tr>
<tr>
<td>Freestanding radiation therapy</td>
<td>1</td>
</tr>
<tr>
<td>Pathology laboratory</td>
<td>1</td>
</tr>
<tr>
<td>Ambulatory treatment center</td>
<td>1</td>
</tr>
</tbody>
</table>
Table 3. Utah Cancer Registry (registry size = 16,186 cases, 1998–1999).

<table>
<thead>
<tr>
<th>Source</th>
<th>Percent Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>91.3</td>
</tr>
<tr>
<td>Pathology laboratory</td>
<td>7.2</td>
</tr>
<tr>
<td>Physician office</td>
<td>0.8</td>
</tr>
<tr>
<td>Nursing home</td>
<td>0.3</td>
</tr>
<tr>
<td>Autopsy</td>
<td>0.2</td>
</tr>
<tr>
<td>Death certificate</td>
<td>0.2</td>
</tr>
</tbody>
</table>

Issues and Challenges Associated With Cancer Ascertainment

Central cancer registries face several external challenges associated with case reporting. The first major group of challenges specifically addresses cancer-reporting facilities. When reliance is on another party to send in relevant cases, the major assumption is that the person responsible for sending the case knows and understands what cases are reportable. However, this is not always true. There are inconsistencies in the education and training levels of the staff from different reporting facilities. These educational variations also may lead to inconsistencies in abstracting and coding of cases, which ultimately would diminish the quality of the data at the registry level (hospital or central). Additional challenges facing registries include high staff turnover rates and inadequate cross-training within a reporting facility. Thus, when one staff person quits his or her job or is otherwise temporarily unavailable (e.g., maternity leave, illness, vacation), there may not be a replacement who has the same depth of knowledge and understanding.

The second major group of external challenges reflects legal barriers to data access. One example is the Health Insurance Portability and Accountability Act (HIPAA) currently being implemented in health care facilities throughout the United States. HIPAA has raised confusion among reporting facilities and medical providers as to whether or not they are required or allowed to continue reporting cancer cases to central cancer registries, or precisely what information (identifiable versus nonidentifiable) to report. As a result of this confusion and because of the fear of repercussions for violating patient privacy and confidentiality, many hospitals and medical providers are opting to remain conservative and not report cancer cases to central cancer registries. If issues surrounding HIPAA remain unresolved, they could adversely impact the completeness of cancer reporting, particularly for cancers such as melanoma and prostate that already are suspected of being underreported by medical providers.

Proposed Solutions

To address the first set of external challenges, NAACCR recommends training registry staff at reporting facilities as well as others in the medical community who help identify reportable cases. Education about cancer registration is needed wherever case ascertainment is conducted. It may be advantageous for registrars at each reporting facility to address the need for cancer reporting as well as for cooperation and continuing education between the registry and other hospital clinical components. In light of recent changes, the medical community also needs to be educated on legislation that mandates the reporting of cancer to a central cancer registry.

NAACCR has obtained an in-depth academic interpretation of the impact of HIPAA legislation on cancer incidence reporting to central cancer registries. Summarized briefly, this interpretation states that HIPAA privacy regulations do not limit disclosures of data on reportable diseases like cancer, by hospitals and medical providers, to cancer registries considered to be public health authorities (i.e., central cancer
registries). In fact, the HIPAA privacy regulations encourage and support the disclosure of cancer data without specific, informed consent from patients for public health purposes. This interpretation was reviewed by NAACCR’s legal counsel, who agreed with its conclusions and documented his legal opinion. The full academic interpretation and the legal opinion letter are included in Appendix H.

Registries requiring followup information (i.e., SEER registries) face yet an additional challenge created by HIPAA—medical providers who are unwilling to report followup information to hospital and/or central registries without the prior informed consent of individual patients. Results of an intense review of the HIPAA rules by NAACCR and an expert attorney led to the conclusion that as long as hospitals are required by law to perform cancer reporting, they meet the definition of a “public health authority.”

Covered entities, such as private physicians, may report protected health information of cancer patients to hospital cancer registries without the written consent or authorization of the individual patient under certain circumstances and for certain purposes, including public health activities.

Internal Challenges

Central registries also face several internal challenges. These include inadequate staffing, inadequate funding for operations, and slow adoption of new technology and tools. Without adequate staff who have the required education and experience, it is difficult for a central registry to ascertain all reportable cases. Central registries require sufficient funding to perform the necessary tasks associated with cancer registration. Often, sources beyond the major funding agency need to be explored to fully support registry operations. This becomes especially important in light of the need for new technologies to keep up with changes in hospitals. For example, as hospitals and pathology laboratories become paperless, many of the tasks that used to be manual (i.e., casefinding, case abstracting, and editing) now are performed electronically. Central registries, therefore, need to have access to electronic technology that has the capability to track case completeness and perform other registry functions.

The Case Ascertainment Process in the United States

The process for cancer case reporting to central registries from a reporting facility’s perspective is presented in Figure 2. This process begins with identifying reportable cases. Most hospital registries have reportable lists provided to them from their central cancer registries. Once reportable cases have been identified, the hospital registrar, cancer reporter, or abstractor from the central registry produces case abstracts and makes certain visual and computer-based quality or validation checks (e.g., EDITS) on these abstracts before submitting them to the central cancer registry. Depending on the size of the reporting facility, abstracts may be transmitted weekly, monthly, or based on a predetermined number of completed abstracts (e.g., 100). Some small hospitals do not create abstracts, but instead submit complete or partial medical records or pathology reports to the central cancer registry. In these cases, the central registry creates abstracts based on the information received.

Case abstracts are reported to the central cancer registry either on paper or electronically. If cases are reported on paper, the central cancer registry creates electronic abstracts either by data entry or scanning into an optical character imaging system. Abstracts then are edited visually and with an electronic editing program (e.g., EDITS, SEER Edits, in-house edits). If at any stage of the transformation or validation process there is a discrepancy that requires clarification, the reporting facility is contacted and communication is maintained until the central registry is certain that the data are correct. Subsequently, cases are matched against, and consolidated with, previously reported data. Linked and consolidated data are validated visually and electronically to identify any data validation issues that require resolution.
Figure 2. Data reporting to central cancer registry from health care facility (with partners’ responsibilities).
A political environment that supports and encourages registry activities is vital to the efficient reporting of quality data. Legal mandates regarding qualifications of abstractors, cancer registrars, and other cancer reporters are helpful, as is support for training. It is recognizably difficult to recruit and retain qualified individuals in the cancer registry profession. Consequently, forming partnerships with professional organizations and dedicating resources to training registry staff have proved to be beneficial. An active state cancer registry association, as well as survivor and activist groups, help to foster a positive political environment. Educating legislators for statutory changes also may be productive.

Effective cancer reporting depends on the relationships between the central cancer registry and its various reporting facilities in addition to the legal mandates. One way that central registries can ensure good relationships is through clear communication with registrars and other key personnel at reporting facilities, specifically by providing updates on such matters as changes in recommendations from standard setters, training opportunities, and relevant staff changes. Central cancer registries are encouraged to provide detailed manuals that clearly state data reporting expectations. Some central registries may provide case reporting software to hospital cancer registries within their region, state, or province. The active support of hospital registry staff by central cancer registry field staff can enhance these relationships. Examples of support from the central cancer registry include help with case abstraction, maintenance of a reporting facility’s cancer database, providing followup information, training, and timely feedback.

Several internal central registry procedures also ensure the quality and efficiency of data reporting. These include visual editing and recoding audits. NAACCR recommends the use of the EDITS program on all data at the time of their submission. Having clearly defined deadlines and sharing them with hospital cancer registries is effective for obtaining timely, quality data.

The Case Ascertainment Process in Canada

Typical mechanisms for case identification in Canada include the following:

- **Source Pathology Records:** Most Canadian registries rely on good reporting relationships (electronic or manual) with the various pathology laboratories in their jurisdictions to receive notification of any case that mentions malignancy or meets case reportability guidelines (e.g., benign brain tumors). Pathology laboratories in Canada typically are hospital-based, although the presence of private laboratories is increasing. Many central registries also have relationships with other laboratories that may be involved in cancer diagnosis (e.g., cytology and hematology laboratories).

- **Hospital Discharge Records:** Case identification through hospital discharge records can occur locally or at a provincial level and can be manual or electronic. In Canada, hospitals are required to complete discharge abstracts (by a health record coder who analyzes the chart post visit) within 30 days of an inpatient or day surgery discharge. The coder assigns diagnostic disease codes and procedure codes using the ICD-9, ICD-9 CM (soon to be ICD-10 CA), along with the Canadian Classification of Procedures, soon to be the Canadian Classification of Interventions.

- **Regional Cancer Centers:** Most registries have a reporting relationship (manual or electronic) with their provincial/regional cancer centers to report newly referred cases.

- **Vital Statistics:** Almost all provinces conduct record linkage (manual and electronic) with their provincial/vital statistics department to receive notification of deaths that have a cancer cause or comorbidity.
- **Special Case Report Forms:** A small number of registries have a special reporting form (manual or electronic) for physicians or hospitals to report new cases.

- **Reciprocal Notification Programs:** If a registry enrolls a case from another province, it typically will notify the correct province if the proper agreements are in place.

- **Other:** Some unique, province-specific strategies that take advantage of local circumstances or resources should be explored (e.g., linkage to breast screening datasets, physician office contacts).

**Improving the Case Ascertainment Process**

There often are a variety of steps that can be taken to improve case ascertainment. NAACCR recommends the following strategies:

- Train all staff who conduct casefinding and case reporting, regardless of work location
- Build relationships with the staff of reporting facilities
- Define expectations (e.g., early meetings with registries to involve them in the definition of yearly expectations from both sides)
- Monitor and maintain expectations
- Explain the value of the data
- Provide state/national established EDITS metafiles to reporting facilities
- Audit casefinding and reporting practices to identify and reconcile gaps (e.g., educational tools/opportunities)
- Improve matching and consolidation software at central cancer registries
- Maintain education/training of staff at the central cancer registry and cancer reporting facilities
- Increase electronic reporting
- Improve timeliness of response to reporting sources.

**Identifying Missed Cases**

To identify missed cases, NAACCR recommends the development of a list of reportable cases to use for casefinding with the disease index and pathology reports. For casefinding using the disease index, NAACCR recommends adoption of the most inclusive list, which currently is the SEER casefinding list (ICD-9, ICD-10). An example of a central registry casefinding list is included in *Appendix I*. Additionally, NAACCR recommends the adoption of SEER conversion books, or crosswalks, for ICD-9 to ICD-10 and for ICD-10 to ICD-9.
Guidelines and Recommendations

NAACCR makes the following recommendations regarding what should be included in a casefinding list:

- State-specific case reportability requirements driven by legislation/regulation
- Registry-specific reportability requirements (e.g., benign brain tumors, CIN III)
- Historical site/histology reporting timelines (e.g., borderline malignancy of the ovary).

Developing a complete case reportability list initially can require large amounts of work for central registries that do not have one in place. However, having such a list will save time in the long run by increasing the efficiency of the casefinding process.
Guidelines for Data Acceptance/Rejection

Most registry directors agree that submission of incomplete or incorrect data is costly in terms of time, staff, efficiency, and quality. Abstractors with less training or experience may, in some instances, write down everything, including irrelevant information, which increases the time it takes to review a case.

To address this issue, NAACCR recommends the use of guidelines discussed earlier in this document. In addition, NAACCR recommends appropriate training for staff at central cancer registries and at the reporting facilities. NAACCR also encourages the establishment of quality improvement procedures at both reporting facilities and central registries. Demonstrated improvement in the case ascertainment process not only helps central cancer registries, but also benefits hospitals that are audited by ACoS (i.e., accredited hospital cancer registries).

Central registries have developed a variety of ways to provide training and support to their reporting facilities. The Oregon State Cancer Registry established an Internet group that registrars throughout Oregon use to post questions about cancer registry operations and data abstraction, as well as to respond to each other regarding casefinding and case-reporting issues. The Illinois State Cancer Registry provides the EDITS program to its electronic reporting institutions for their use prior to data submission. As a result, these central cancer registries now report fewer errors in case submissions because of the increased knowledge of hospital registry staff.

Registries also employ several mechanisms to ensure and maintain quality training for their staff. For example, at the Karmanos Cancer Institute in Detroit, MI, 100 percent of cases abstracted by abstractors who have less than 3 years of experience are visually edited. However, visual editing does not have much value unless there is a feedback mechanism to abstractors that documents and illustrates to them where mistakes were made, and follows them forward to note improvements. Not every registry has the staffing or resources to do this.

Registries are encouraged to keep all staff and reporting facilities well informed of updates on standards released from NAACCR, as well as the process and timeframe for their implementation. This may be accomplished in several ways, including the use of e-mail listservs and newsletters.

In addition, NAACCR makes the following recommendations for establishing procedures to accept or reject a case:

- Provide EDITS software to reporting sources
- Maintain strong relationships with reporting sources so that registries can appreciate and provide appropriate assistance for editing issues/problems as they arise
- Provide up-to-date EDITS metafiles and education to reporting facilities
- Reject data files that do not meet criteria established by the central registry
- Encourage hospital cancer registries to guarantee that vendors use EDITS metafiles to ensure high-quality data submissions to central cancer registries
- Make expectations very clear (central registry to vendor, central registry to hospital registry).
Rationale for Case Acceptance

Cases are accepted based on an evaluation of data quality and submission format. Because population-based cancer registries are required to collect all incident cancer cases, there is inevitable tension between the quantity and the quality of reported data. To address these types of issues, many central registries have developed policies and established quality acceptance thresholds to guide their decisionmaking process. An example is included in Appendix K.
Guidelines for Evaluating Interfield Inconsistencies and Discrepancies

Case reports from multiple facilities may have discrepancies that affect case reportability. Central registries use several methods to evaluate and reconcile interfield inconsistencies of site, histology, and behavior. Registries rely on information found in the text provided with the case to verify that the text supports the coded values. Whenever the option arises to override an inconsistent site/type combination, NAACCR recommends that the override be justified and documented in the text. This recommendation is strongly suggested for use with site/type inconsistencies that are considered impossible. However, excessive use of the override option may be a marker of poor data quality.

The methods for addressing discrepancies in information from the various reporting sources may differ by central registry. When the text that accompanies a cancer case submission to a central cancer registry does not support the codes, some central registries (e.g., Oregon State Cancer Registry, Pennsylvania Cancer Registry) will send the reporting facility a discrepancy letter to ask for clarification. In Illinois, when the site/histology combination is inconsistent, the State Cancer Registry does not send discrepancy letters to hospitals with registries, but does send letters to all other reporting facilities. However, when the site/histology combination is impossible, all reporting facilities in Illinois receive a discrepancy letter from the registry. The site/histology impossible cases are changed (based on the error correction help of the Primary Site, Morphology-Impossible [SEER IF38] edit-specific guidelines described in greater detail in NAACCR Standard Data Edits Volume IV) when there is no documentation to support the codes. The Illinois process of reconciling site/morphology discrepancies generated from EDITS. A copy of the Illinois discrepancy letter are included in Appendix J. Other central registries (e.g., New York State Cancer Registry) may call the reporting facility for clarification. When the code for the given case is not possible (or is “impossible”), registries usually do not override or accept the codes. Instead, hospitals are asked to verify the codes. The Pennsylvania Cancer Registry has found that hospitals are usually quick to see the mistakes once they are pointed out, and quick to make the appropriate changes.8
References


Appendices

Appendix A: U.S. Census Bureau Residency Rules

Appendix B: Examples of Central Cancer Registry Procedures for Obtaining Cancer Cases From Physician Offices

Appendix C: Example of Central Cancer Registry Pathology Laboratory Nonelectronic Reporting Procedures

Appendix D: NAACCR-Recommended Central Cancer Registry Reportable List

Appendix E: Example of ICD-CM Code List

Appendix F: Examples of Central Cancer Registry State Laws

Appendix G: Example of Central Cancer Registry Nonreportable List

Appendix H: Academic Letter Interpreting HIPAA; Legal Letter Interpreting HIPAA

Appendix I: Example of Central Cancer Registry Casefinding Procedures and List

Appendix J: Example of Central Cancer Registry Procedures for Evaluating Inconsistencies Between Data Items; Example of Discrepancy Letter

Appendix K: Example of Central Cancer Registry Case Acceptance Policies
Appendix A: U.S. Census Bureau Residency Rules


SUGGESTED ADAPTATION OF CENSUS RULES FOR DETERMINING RESIDENCY
BY CENTRAL CANCER REGISTRIES

VACATION OR BUSINESS
People temporarily away on vacation or a business trip on day that the cancer is documented—residence should be documented as their usual residence, that is, the place where they live and sleep most of the time.

PEOPLE WITHOUT HOUSING
People without a usual residence—residence should be documented as the place where they are staying on the day that the cancer is documented.

PEOPLE WITH MULTIPLE RESIDENCES
Commuter workers living away part of the week while working—residence should be documented as where they stay most of the week.

Snowbirds (people who live in one state but spend the winter in another state with a warmer climate)—residence should be documented as where they live most of the year. If time is equally divided by location, SEER recommends that their residence be the place where they are staying on the day that the cancer is documented.

Children in joint custody—residence should be documented as where they live most of the time. If time is equally divided, their residence is documented as where they are staying on the day the cancer is documented.

People who own more than one residence—residence should be documented as the place where they live most of the time.

STUDENTS
Boarding school students—residence should be documented as their parental home rather than at the boarding school (for students under 18 years).

College students living away from home while attending college—residence should be documented as the place where they are living at college.

College students living at their parental home while attending college—residence should be documented as their parental home.
**Live-Ins**

*Live-in nannies*—residence should be documented as where they live most of the week.

*Foster children*—residence should be documented as where they are living.

*Roomers or boarders*—residence should be documented as where they are living.

*Housemates or roommates*—residence should be documented as where they are living.

**Military or Merchant Marine Personnel in the United States**

*People in the military residing in the United States*—residence should be documented as their usual residence (the place where they live and sleep most of the time), whether it is on-base or off-base.

*Crews of military vessels with a U.S. homeport*—residence should be documented as their usual onshore residence if they report one (the place where they live and sleep most of the time when they are onshore) or otherwise at their vessel’s homeport.

*Crews of U.S. flag merchant vessels engaged in inland waterway transportation*—residence should be documented as their usual onshore residence (the place where they live and sleep most of the time when they are onshore).

*Crews of U.S. flag merchant vessels docked in a U.S. port or sailing from one U.S. port to another U.S. port*—residence should be documented as their usual onshore residence if they report one (the place where they live and sleep most of the time when they are onshore) or otherwise on the vessel.

**People in Hospitals, Prisons, or Other Institutions**

*Patients in general hospitals or wards, including newborn babies*—residence should be documented as their usual residence (the place where they live and sleep most of the time). Residence of newborn babies should be documented as where they will be living.

*Patients in chronic or long-term disease hospitals or wards*—residence should be documented as the hospital or ward.

*People in nursing or convalescent homes for the aged or dependent*—residence should be documented as the nursing or convalescent home.

*Patients staying in hospice facilities*—residence should be documented as the hospice.

*People staying in homes, schools, hospitals, or wards for the physically handicapped, mentally retarded, or mentally ill; or in drug/alcohol recovery facilities*—residence should be documented as the institution.

*Inmates of correctional institutions, including prisons, jails, detention centers, or halfway houses*—residence should be documented as the institution.

*Children in juvenile institutions such as residential care facilities for neglected or abused children or orphanages*—residence should be documented as the institution.
Staff members living in hospitals, nursing homes, prisons, or other institutions—residence should be documented as what they report to be their usual residence (the place where they live and sleep most of the time) or otherwise at the institution.

People in Noninstitutional Group Quarters
Migrant farmworkers—residence should be documented as their usual U.S. residence if they report one (the place where they live and sleep most of the time) or otherwise at the workers’ camp.

People at hostels, YMCAs/YWCAs, or public or commercial campgrounds—residence should be documented as their usual residence if they report one (the place where they live and sleep most of the time) or otherwise at the hostel, etc.

Members of religious orders living in monasteries or convents—residence should be documented as their usual residence if they report one (the place where they live and sleep most of the time) or otherwise as the monastery, etc.

People staying at Job Corps or other post-high school residential vocational training facilities—residence should be documented as their usual residence if they report one (the place where they live and sleep most of the time) or otherwise as the Job Corps Center, etc.

People at soup kitchens or mobile food vans—residence should be documented as their usual residence if they report one (the place where they live and sleep most of the time) or otherwise at the soup kitchen, etc.

Shelters with sleeping facilities for people without housing, for abused women, or for runaway or neglected youth—residence should be documented as the shelter.

Foreign Citizens
Citizens of foreign countries who have established a household or are part of an established household in the United States while working or studying, including family members with them—residence should be documented as the household.

Citizens of foreign countries who are living in the United States at embassies, ministries, legations, or consulates—residence should be documented as the embassy, etc.

Citizens of foreign countries temporarily traveling or visiting in the United States—These cases are not reportable to U.S. central cancer registries.
Appendix B: Examples of Central Cancer Registry Procedures for Obtaining Cancer Cases From Physician Offices

Example of Physician Reporting Procedures

Nebraska Cancer Registry

- Each pathology laboratory in Nebraska sends either a listing or a copy of their reportable cases reviewed through their facility. (Some laboratories report on a regular basis; others report when requested. Some out-of-state laboratories report cancer cases for Nebraska residents.)

- Each pathology report is reviewed to exclude those cases that have been reported by a hospital or dermatology office. The remainder of cases are sorted by the facility or physician’s office submitting the tissue.

- Hospitals are sent a list of the cases not reported but belonging to their facility to assist with their casefinding.

- For those cases with tissue submitted through a physician’s office or clinic, a form is prepared to fill in as much information as is available on the pathology report.

- Some state cancer registries offer the option that, if more than five cases are diagnosed in the year, registry staff will visit their office and abstract the cases for them.

- Letters are sent on a quarterly basis to minimize the number of forms sent to physicians. Slow hospital reporting does affect the number of forms sent. Some hospitals are collecting class of case by reviewing reports from their pathology laboratories. When the College no longer required physician office only cases, physicians at several facilities wanted their registrars to continue collecting the cases. These cases do not need to be abstracted by central registry personnel, as they are reported with their hospital cases.

- When the form is returned from the physician’s office, the pathology listing is updated and the pathology report is attached to the form. If they indicate that treatment was received in an in-state hospital, we follow back to that hospital. They are advised to include the cases in their registry and submit the information to the central office.

- Each pathology laboratory is assigned a hospital number, so the cases from physicians’ offices are entered using this number as the hospital assigned to the case. “Report source” is coded as 3 pathology laboratories. The “class of case” is coded as 0 or 1, depending on whether they were only diagnosed or received treatment (e.g., lupron, excision biopsy, etc.) in the physician office. If a case is later received from a hospital, the report source for the consolidated record is changed to 1 (hospital).

- Several dermatology offices have cancer registry forms on file. When a malignant melanoma case is diagnosed, they submit the information. These are coded “report source” 4 (physician office) with a 3-digit hospital code for the dermatology office.
New Jersey State Cancer Registry

Physicians in New Jersey are required to report all nonhospitalized cancer patients diagnosed and/or treated in their offices within 6 months of diagnosis to the New Jersey State Cancer Registry (NJSCR).

All newly licensed physicians in New Jersey receive a packet from the New Jersey Department of Health and Senior Services (NJDHSS) outlining the procedures for reportable diseases. Information pertaining to reporting cancer is included in this packet.

The NJSCR requires physicians to complete a simple 1-page physician report form. The completed form can either be faxed or mailed to the NJSCR. A copy of the Physician Report Form is available on the Internet for physicians to download. An instruction manual outlining procedures for how to complete the form and how to report to the NJSCR is available for all physicians.

The NJSCR takes a proactive approach in identification of physicians diagnosing and/or treating nonhospitalized cancer patients. The following measures are taken to ensure complete reporting:

- In addition to the mailing to newly licensed physicians conducted by the NJDHSS, the NJSCR conducts statewide physician mailings periodically. In general, these mailings target physician specialties such as dermatologists, urologists, general surgeons, hematologists, oncologists, and radiation oncologists to remind them to report to the NJSCR. Mailing addresses for these physicians are obtained from the Bureau of Licensing within the NJDHSS. A packet containing a cover letter outlining the physicians obligation to report nonhospitalized cancer patients; a copy of New Jersey regulations; physician report forms and an instruction manual are sent to the physicians.

- In addition to information received from the Bureau of Licensing, we identify large physician practices; ambulatory care centers and radiation treatment facilities through hospital tumor registrars. Often, tumor registrars lose patients to new out patient facilities opening in their local area. Through frequent communication and monitoring of case reporting from hospitals, we are able to identify physician practices that are diagnosing and/or treating patients outside of the hospital setting. Newly identified practices are sent a packet of information outlining procedures to report to the NJSCR.

- Physicians also are identified from reports that have been sent to the NJSCR from private pathology labs. If a case is reported from a private pathology lab and has not been previously reported from a physician or hospital, a partially completed physician report form is sent to the physician requesting them to report the case. If the physician report form is not returned to the NJSCR within 2 months, a followup request is made to the physician.

- Physicians also are identified from death certificates. If a case is identified from a death certificate and has not been reported, a partially completed physician report form is sent to the physician requesting them to report the case. If the physician report form is not returned to the NJSCR within 2 months, a followup request is made to the physician.

- The NJSCR is available to speak to professional physician societies and organizations to discuss the importance of reporting.

- The NJSCR is available to visit physician’s offices and ambulatory centers to train physician office personnel in case identification and reporting procedures.
• The NJSCR collaborates with the Tumor Registrar Association of New Jersey (TRANJ) on several educational programs. In particular, we work closely with TRANJ on a Basic Education Program that is offered monthly for new tumor registrars. Various physicians from throughout the State of New Jersey such as surgeons, oncologists, present at each of these workshops. Through their participation in this program, physicians have in turn been educated about the Registry and the importance of reporting.

• The NJSCR provides support and encouragement and training to hospital tumor registrars that report cases to the NJSCR for private physician practices.

Example of Procedures for Identifying Cases Seen Only in Physician Offices

Utah Cancer Registry

• The Utah Cancer Registry (UCR) identifies all pathology reports from tissue removed in physician offices from private pathology laboratories, both in state and out-of-state, and sends followup letters to the physician on the report to obtain more complete information.

• Letters are periodically sent to all physicians in the state notifying them of Utah’s reportability regulation (law) and asking them to directly report all malignancies that are not seen in Utah hospitals or that did not have a pathology specimen that was sent to a Utah pathology laboratory.

• Last year, a letter and survey were sent to all dermatologists in Utah to ask where they are sending their slides and if they are reading slides in their office.

• In the future, the UCR intends to send a similar letter to urologists and other specialists who tend to see patients only in the outpatient setting.
Example Letter

Dear Doctor:

Cancer is a reportable disease in [STATE] and must be reported to the [STATE] Central Cancer Registry within 6 months of diagnosis. Physicians are required to report all nonhospitalized patients who are diagnosed/treated in their offices. Because many cancer cases now are being diagnosed in outpatient settings, we need to capture more information solely from pathology laboratories and physicians to have a complete registry.

Most cancer cases seen in [STATE] are reported to the [STATE] Cancer Registry by hospitals and laboratories, and do not require reports from individual physicians. However, if a physician sees a reportable cancer case that has never been hospitalized or whose tissue was never reviewed in a pathology laboratory in [STATE], it is the responsibility of that physician to report the case to the [STATE] Cancer Registry.

In an effort to streamline reporting and improve compliance, a physician reporting form has been developed. All required demographic, medical, and treatment information is included on this form. If you refer your patient elsewhere for diagnosis and/or treatment, please be sure to record the name and address of the referral physician on this form. Enclosed please find a supply of reporting forms, an instruction manual, and a copy of the regulations. If you have any questions or need a new supply of forms, please contact our physician liaison representative, [NAME], via telephone [TELEPHONE NUMBER], fax [FAX NUMBER], or e-mail [E-MAIL ADDRESS].

For any physician or practice reported to have five or fewer patients with missing or incomplete cancer registry information, we ask you or your office staff to provide the information. The supplemental information we are asking from you should be available in your office records, and your staff should be able to supply this information in most cases. The requested information is necessary for us to complete the Cancer Registry record on these patients. (If you have five or more patients with outstanding information, the Cancer Registry can provide personnel to assist your office in obtaining the necessary data.)

The [STATE] Cancer Registry strives to collect as much information as possible regarding reportable cancer cases from hospitals and pathology laboratories. However, we sometimes contact private physicians’ offices to ascertain information that is not available from other sources. Such inquiries are made only after all other sources have been exhausted. We may call your office or send one of the following forms to your office to collect information for such cases:

- Monthly followup letters, which are sent to the attending physician 1 year from the date we have received any followup information for a patient.

- Annual forms labeled “Follow-Back Form for Pathology Reported Cases,” requiring additional data for the previous year’s cases that were reported to us only from a [STATE] pathology laboratory. These forms are sent to you if the pathology report listed you as the patient’s physician.

- Annual forms labeled “Follow-Back Form for Death Certificate Reported Cases,” requesting data for the previous year’s cases that were reported to us only from a death certificate, which was signed by you.
I want to emphasize that we are required by law to keep all patient-specific cancer information strictly confidential.

While we have attempted to minimize the additional work required on your part to collect the information needed by the Cancer Registry, we understand that it still takes time. We are grateful for your cooperation and welcome any questions or comments you have that might improve the process.

Thank you for supporting our cancer surveillance efforts in [STATE]. If you are interested in receiving age-adjusted incidence rates for cancer in [STATE], please contact our office or visit our Web site at [WEB SITE].
Example Physician Report Form

Patient Name: ________________________________  DOB: ______________  Gender: _________
Address at Diagnosis: ________________________________________________________________

SSN: ______________  Race: ______________  Occupation: _________________________
Marital Status: _________________________
Primary Cancer Site: ______________________________  Date of Diagnosis: ______________
Histology: ___________________________________________________________________________
Paired Organ (left/right side, bilateral): ___________________________________________________________________________

Was Patient Hospitalized for This Cancer?  □ Yes  □ No
If Yes, Name of Hospital: ______________________________  Date: ______________
Is This the Patient’s Only Primary Neoplasm?  □ Yes  □ No  □ Unknown

Method of Diagnosis of This Cancer:  
□ Positive histology  □ Positive cytology  □ Autopsy
□ Positive laboratory test marker study  □ Radiography  □ Direct visual
□ Clinical  □ Method unknown

Stage at Diagnosis:  
□ In situ  □ Localized  □ Regional by direct extension
□ Regional to lymph nodes  □ Regional by direct extension AND to lymph nodes
□ Regional, NOS  □ Distant metastases/systemic disease
□ Unstaged, unknown, or unspecified

Has this patient had any of the following treatments?

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Yes/No</th>
<th>Date</th>
<th>Procedure and Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy/Hormone Therapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation Therapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Physician Responsible for Ongoing Cancer Therapy/Care: ______________________________________
Address: __________________________________________________________
Telephone: ____________________________________________
Date of Last Followup: ____________________________

**Patient Status:**
- □ Alive, free of cancer
- □ Alive, evidence of cancer
- □ Alive, cancer status unknown
- □ Deceased, free of cancer
- □ Deceased, evidence of cancer
- □ Deceased, cancer status unknown

Followup Contact/Next of Kin Name: ____________________________
Address: ____________________________________________
_____________________________________________________
Utah Cancer Registry

Survey of Utah Dermatologists

(1) For each type of skin lesion listed below, please indicate how often you send pathology specimens to a dermatopathologist or other pathologist outside your office for diagnostic evaluation and/or review:

Pathology specimens sent outside your office for diagnosis/review
(choose one for each type of lesion)

<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>(A) Lentigo maligna</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(B) Frank melanoma</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(C) Questionable melanoma</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(D) Non-basal, non-squamous cell skin cancers (i.e., Merkel cell, angiosarcoma, etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(2) If you send pathology specimens to a dermatopathologist or other pathologist outside your office for diagnostic evaluation and/or review, please list below all such individuals/laboratories that you utilize:

<table>
<thead>
<tr>
<th>Pathologist/Pathology laboratory</th>
<th>Address</th>
<th>Telephone number</th>
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</table>

(3) The Utah Cancer Registry would like to work with you and your office staff to develop an agreeable method for reporting those cases of malignant melanoma and other non-basal, non-squamous cell skin cancers that are not reviewed outside of your office. Please indicate which of the following choices best meets your needs:

_____ I prefer to report such cases directly to the Utah Cancer Registry using standardized forms that have been developed for cancer reporting.

_____ I would like to discuss other options for reporting such cancer cases to the Utah Cancer Registry.

Please return to: Charles Wiggins, Ph.D., Director
Utah Cancer Registry, 546 Chipeta Way, Suite 2100, Salt Lake City, UT 84108
Appendix C: Example of Central Cancer Registry Pathology
Laboratory Nonelectronic Reporting Procedures

- Illinois

Illinois State Cancer Registry

Guidelines for Laboratory/Dermatology Reporting

1. Complete an ISCR Incidence Report Form for each reportable case. Use black ink and all capital letters. Attach a copy of the laboratory/pathology report to each case reported. If there is not a laboratory/pathology report attached to the incidence report form, ISCR cannot process the case and it will be returned for further information.

   NOTE: Dermatologists report only malignant melanomas.

2. Send a batch submittal form indicating the total number of cases being submitted. A batch submittal form is included in the manual. Please copy this form as needed.

3. Retain a copy of the reports for your records, along with any notes or supporting documentation submitted.

4. Cancer incidence submittal should be done monthly.

5. Submit the incidence report forms with the batch submittal form from your facility to the:

   ILLINOIS DEPARTMENT OF PUBLIC HEALTH
   DIVISION OF EPIDEMIOLOGIC STUDIES
   ILLINOIS STATE CANCER REGISTRY
   605 W. JEFFERSON STREET
   SPRINGFIELD, IL  62761

6. If you have specific questions, you may call Sharon White, CTR, at 217-785-7123 or e-mail at swhite@idph.state.il.us.
Illinois State Cancer Registry Pathology Laboratory Reporting Procedures

1. Upon receipt of pathology laboratory report forms (those with facility numbers 4001-4040), check to make sure that there is a pathology report attached to each form. If not, return the form with the appropriate cover letter (pathret2.wpd), asking that a path report be attached before resubmitting the case.

2. Visually check the reports for any incidence that is not reportable to the Illinois State Cancer Registry (ISCR), including nonreportable tumors and/or out-of-state residents. If any are found, return them to the reporting facility with the appropriate cover letter (pathret1.wpd).

3. Complete sequence, date of diagnosis, primary site, laterality and morphology at the bottom of each form. Refer to Rocky Mountain Cancer Data Systems (RMCDS) to determine sequence, to the pathology report for the diagnosis date, and to ICD-O-3 for the primary site and morphology codes. If when referring to RMCDS a case is found to be class 3, make a note in the Comments section and set aside. This case will not be entered.

4. Assign the physician contact number for the physician on each form. These numbers are found in the Access Lab Database, Contact Table. Assign a new contact number for any physician not in the table. To do this, go to Forms, Contact Data Entry, and assign the next number available, Facility Name (if applicable), Contact Name (FN LN), Street Address, City State, Zip Code, and Telephone Number.

5. Enter required data into the Access Lab Database, Forms, Data Entry (using the appropriate diagnosis year). These required data items include Facility ID, Patient Name (LN, FN), Social Security Number, Date of Birth, Date of Diagnosis, Site Code, Site Text, Laterality, Morphology Code, and Contact Number.

6. File the incident report forms in alphabetical order in the appropriate folders by diagnosis year, including the class 3s that were not data entered.

7. In January of each year, using the Automatch program (contact Data Management Supervisor when this is ready to be performed), match the Lab Database cases for the target year against RMCDS.

8. Using the list generated by the Automatch process, review the cases that were not matched to the main database. Be sure to “match” any cases on the list that have a match in the Lab Database Table (for the corresponding diagnosis year).

9. Pull the incident report forms for the remaining nonmatched cases and keep them filed separately from the matched cases.

10. Run follow-back letters from Lab Database, Reports, (dx yr) Followup letters (Dr). Print the letters and generate the corresponding labels, also in the Report section of the Lab Database. Be sure to enclose an ISCR return envelope with the letter.
11. When a follow-back letter is returned indicating an Illinois reporting facility as having administered staging and or work-up, contact that facility to determine whether the case has, in fact, been missed. If identified as missed, ask them to report with the next ISCR submission. Approximately 1 month after requesting submission of the case, check RMCDS to verify that it has actually been reported. If not, call and remind the facility to send the case.

12. A second follow-back letter, when necessary, is submitted ONLY for prostate and melanoma cases.

13. After all follow-back efforts have been exhausted for diagnosis year cases, complete an ISCR abstract form for any of those cases that remain unmatched to the main database.

14. All follow-back should be completed by July 1 following the January Automatch run.

15. The ISCR abstracts completed for unmatched cases are then batched by facility ID number and given to the designated person for logging.

16. If any EDITS reports are generated for any of these facilities when merged onto RMCDS, they will be returned to you for correction.

17. Annually, after follow-back has been completed, note any pathology laboratories that have not submitted ANY cases for the previous year. Make a telephone contact to attempt to find out a reason for no submissions. Make any necessary changes to the facility listing (i.e., pathology laboratory closed, no longer processing cytology/histology specimens that would diagnose a malignancy).

18. Annually, after follow-back has been completed, request a listing from the Clinical Laboratory Improvement Act (Melinda @2-6747) of active laboratories processing histology and/or cytology specimens (including laboratory types 11, 19, and 23) and a listing of active Association of Science-Technology Centers (ASTCs) (laboratory type 01). Review the lists to determine if any new laboratories or ASTCs have become active since the prior list was reviewed.
Appendix D: NAACCR-Recommended Central Cancer Registry Reportable List

This Recommended List of Reportable Conditions provides documentation of all conditions NAACCR considers reportable. 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. An asterisk (*) to the right of a term denotes conditions not reportable when arising from skin except at a mucoepidermoid site as defined under Exclusions below. The abbreviation “NOS” means “Not Otherwise Specified.”

Please note that state or provincial specific differences may exist, and that states or provinces may modify this list to suit their special needs.

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) also are included in this listing.

Determining Reportable Conditions Using ICD-O Behavior Codes

All cases with a behavior code of /2 (in situ) or /3 (malignant) in the International Classification of Diseases for Oncology (ICD-O), are reportable neoplasms. In addition, juvenile or pilocytic astrocytoma with a behavior code of /1 (uncertain/borderline) in ICD-O, Third Edition also is reportable using a behavior code of /3.

Note: If a pathologist verifies an ICD-O behavior code of /0 (benign) or /1 (uncertain) as “in situ” or “malignant,” these cases are reportable.

Exclusions

Conditions are not to be reported if the diagnosis includes:

- Squamous and basal cell cancers primary to the skin:
  - Neoplasms, malignant, NOS of the skin (C44.0-C44.9)
  - Epithelial carcinomas of the skin (C44.0-C44.9)
  - Squamous cell carcinomas of the skin (C44.0-C44.9)
  - Basal cell carcinomas of the skin (C44.0-C44.9)

  Note: The above 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, and C63.2).

- Cervical intraepithelial neoplasia (CIN).
- Prostatic intraepithelial neoplasia (PIN).
Changes to December 2000 List of Abbreviated Reportable Conditions:

- Reportable conditions from both the *International Classification of Diseases for Oncology, Second Edition (ICD-O-2)* and the *Third Edition (ICD-O-3)* are included in the listing.

- Newly reportable conditions and terms with behavior changed from /1 (borderline) in *ICD-O-2* to /3 (malignant) in *ICD-O-3* are identified in **bold** print. These conditions are reportable only when diagnosed on or after January 1, 2001.

- Several terms changed behavior from /3 (malignant) in *ICD-O-2* to /1 (borderline) in *ICD-O-3*. These conditions are reportable only when diagnosed prior to January 1, 2001, and are identified in *brackets and italics*.

- New terms and synonyms for existing ICD-O codes were added.

Adamantinoma (long bones, malignant, tibial only)
Adenoacanthoma
**Adenocarcinofibroma**
Adenocarcinoma
Adenofibroma (malignant endometrioid only)
Adenoma (carcinoid bronchial and cylindroid bronchial only)
Adenosarcoma
AIN III (anal intraepithelial neoplasia, grade III)
Ameloblastoma (malignant only)
Androblastoma (malignant only)
**Anemia, refractory**
Angioendotheliomatosis
Angiomyosarcoma
Angiosarcoma
Argentaffinoma (malignant only)
Arrhenoblastoma (malignant only)
Astroblastoma
Astrocytoma (exclude subependymal and desmoplastic infantile)
Astroglia
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)
Cylindroma (exclude eccrine dermal, and skin)
Cyst (dermoid with malignant transformation only or dermoid with secondary tumor)
**Cystadenocarcinofibroma**
Cystadenocarcinoma
Cystadenofibroma (malignant endometrioid only)
[Cystadenoma (diagnosis date prior to January 1, 2001);
(mucinous, borderline malignancy papillary, borderline malignancy papillary mucinous, borderline malignancy papillary pseudomucinous, borderline malignancy papillary serous, borderline malignancy pseudomucinous, borderline malignancy serous, borderline malignancy only)]
Cystosarcoma phyllodes (malignant only)

**Cytopenia, refractory with multilineage dysplasia**

Dermatofibrosarcoma

Diktyoma (exclude benign)

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, NOS**

Paget* [exclude of bone]

Sezary)

**Disorder, myeloproliferative, chronic**

Disorder, primary cutaneous CD30+

T-cell lymphoproliferative

Dysgerminoma

**Ectomesenchymoma**

**Endometriosis, stromal**

Enteroglucagonoma (malignant only)

Ependymoblastoma

Ependymoma (exclude myxopapillary)

Epithelioma* (NOS, basal cell, malignant, and squamous cell only)

Erythremia (acute and chronic only)

Erythroblastosis

Erythroplasia, Queyrat*

Esthesioneuroblastoma

Esthesioneurocytoma

Esthesioneuroepithelioma

Fibrochondrosarcoma

**Fibrodentinosarcoma**

Fibroepithelioma, of Pinkus type or

NOS*

Fibroliposarcoma

Fibromyxosarcoma

**Fibro-odontosarcoma**

Fibrosarcoma

Fibroxanthoma (malignant only)

Ganglioglioma (anaplastic)

Ganglioneuroblastoma

Gastrinoma (malignant only)

Gemistocytoma

Germinoma

**GIST-Gastrointestinal stromal tumor**

(malignant only)

Glioblastoma

Glioma (exclude nasal and subependymal)

Gliomatosis cerebri

Gliosarcoma

Glomangiosarcoma

Glucagonoma (malignant only)

Granuloma (Hodgkin only)

Hemangioendothelioma (malignant only)

Hemangiopericytoma (malignant only)

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 situ only)

Hypernephroma

Immunocytoma

Insulinoma (malignant only)

**LCIS, NOS (lobular carcinoma in situ)**

Leiomyosarcoma

Lentigo maligna

Leukemia (exclude granular lymphocytic)

Linitis plastica

Liposarcoma (exclude well differentiated liposarcoma, superficial)

LN2 (of breast also called lobular neoplasia, grade 2 only)

Lymphangioendothelioma (malignant only)

Lymphangiosarcoma

Lymphoblastoma

Lymphoepithelioma*

Lymphoma

Lymphosarcoma

Macroglobulinemia, Waldenstrom

Malignancy*

Malignant*

Mastocytoma (malignant only)

Mastocytosis (malignant only)
Medulloblastoma
Medulloepithelioma
Medullomyoblastoma
Melanoma (exclude juvenile)
**Melanomatosis, meningeal**
Melanosis (precancerous only)
Meningioma (malignant, anaplastic, papillary, or rhabdoid only)
Mesenchymoma (malignant only)
Mesonephroma (exclude benign)
Mesothelioma (exclude benign and cystic)
**Metaplasia, agnogenic myeloid**
Microglioma
**MPNST, NOS (malignant peripheral nerve sheath tumor)**
Mycosis fungoides
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 endolympathic stromal**
Myxoliposarcoma
Myxosarcoma
Neoplasia, ductal intraepithelial, grade 3 (of breast, also called DIN III)
**Neoplasia, intratubular germ cell**
Neoplasia, lobular, grade 2 of breast only (also called LN2)
Neoplasia, squamous intraepithelial, grade 3 (of anus, vulva and vagina only- also called, AIN III, VIN III and VAIN III)
Neoplasm, malignant*
Nephroblastoma
Neuroblastoma (exclude mesoblastic)
Neurilemmoma (malignant only)
Neurilemmosarcoma
Neuroblastoma
**Neurocytoma, olfactory**
Neuroepithelioma
Neurofibrosarcoma
Neurosarcoma
Nevus (malignant blue only)
Odontosarcoma
Oligoastrocytoma, mixed
Oligodendroglioma
Oligodendroblastoma
Orchioblastoma
Osteochondrosarcoma
Osteosclerotic chordoma
Osteosclerotic plasmacytoma (malignant only)
Osteosarcoma
Pancreatoblastoma
Panmyelosis, acute only
Papilloma, choroid plexus (anaplastic and malignant only)
**Papulosus, lymphomatoid**
Paraganglioma (malignant only)
Paragranuloma, Hodgkin
**Perineural MPNST**
Perineurioma (malignant only)
Pheochromocytoma (malignant only)
Pilomatrixoma* (malignant only)
Pineoblastoma
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**
Pseudomyxoma peritonei
Queyrat erythroplasia*
Reticuloendotheliosis
Reticulosarcoma
Reticulosis (histiocytic medullary, malignant, pagetoid, and polymorphic only)
Retinoblastoma
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)
Spongioblastoma (polar or malignant only)
Spongioneuroblastoma
**Stromatosis, endometrial**
Struma (malignant ovarii and Wuchernde Langhans only)
Sympathicoblastoma
Syndrome, 5q deletion with myelodysplastic syndrome
Hyperesinophilic
Myelodysplastic
- NOS
  - with 5q deletion syndrome
  - therapy-related, NOS
  - therapy-related, alkylating agent related
  - therapy-related, epidopophyllotoxin related
**Preleukemic**
Sezary
Synovioma (NOS and malignant only)
Syringoma chondroid, (malignant only)
Teratoblastoma, malignant
Teratocarcinoma
Teratoma (embryonal, immature, malignant, and with malignant transformation only)
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
  - Bednar
  - beta cell (malignant only)
  - Brenner (malignant only)
  - Burkitt
carcinoid, NOS (except of appendix)
carcinoid (malignant only)
desmoplastic small round cell embolus*
endodermal sinus
epithelial* (malignant only)
Ewing
**fibrous, solitary (malignant only)**
**follicular dendritic cell**
fusiform cell type* (malignant only)
G cell (malignant only)
gastrin cell (malignant only)
gastrointestinal stromal (malignant only)
germin cell
giant cell (malignant only)
**glomerus (malignant only)**
granular cell (malignant only)
granulosa cell (malignant or sarcomatoid only)
Grawitz
interstitial cell (malignant only)
**intraocular bronchial alveolar**
Klatskin
Krukenberg
Leydig cell (malignant only)
malignant* (any type)
mast cell (malignant only)
Merkel cell
mesenchymal (malignant only)
mesodermal, mixed
metastatic*
mixed pineal
mixed salivary gland type (malignant only)
[mucinous, of low malignant potential; diagnosis date prior to January 1, 2001]
mucocarcinoid
Mullerian mixed
neuroectodermal (exclude melanotic)
onencapsulating sclerosing
donodontogenic (malignant only)
olfactory, neurogenic
Pancoast
[papillary mucinous, of low malignant potential; diagnosis date prior to January 1, 2001]
[papillary serous, of low malignant potential; diagnosis date prior to January 1, 2001]
peripheral neuroectodermal or peripheral primitive neuroectodermal, NOS
**peripheral nerve sheath (malignant only)**
phyllodes (malignant only)
pineal parenchymal of intermediate differentiation
Pinkus*
plasma cell
polyvesicular vitelline
Tumor (include only count:
primitive neuroectodermal
rhabdoid, NOS
rhabdoid/teratoid, atypical
round cell, desmoplastic, small
Schminke
secondary*
[serous, NOS, of low malignant potential
serous, papillary, of low malignant
potential; diagnosis date prior to
January 1, 2001]
Sertoli-Leydig cell (poorly
differentiated, with heterologous
elements, sarcomatoid (malignant only)
sinus, endodermal
small cell type* (malignant only)
soft tissue (malignant only)
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
Appendix E: Example of ICD-CM Code List

ICD-9-CM Codes

Use the following ICD-9-CM codes to identify reportable conditions. Conditions in bold type are reportable only when diagnosed on or after January 1, 2001. Conditions in brackets [ ] and italics are reportable only when the diagnosis date is prior to January 1, 2001.

042 AIDS (review cases for AIDS-related malignancies)
140 - 199 Malignant neoplasms
200 - 208 Lymphoma/leukemia/multiple myeloma
230 - 234 Carcinoma in situ (exclude 233.1*)
[235.4] Peritoneum/cystadenoma, borderline malignancy
[236.0] Endolymphatic stromal myosis/endometrial stromatosis/stromal endometriosis/
stromal myosis, NOS
[236.2] Tumor of ovary/cystadenoma, borderline malignancy of low malignant potential
237.5 Papillary ependymoma
237.6 Papillary meningioma
238.3 Phyllodes tumor, malignant (cystosarcoma phyllodes)
238.4 Polycythemia vera
238.6 Plasmacytoma/solitary myeloma
Acute panmyelosis/chronic myeloproliferative disease/myelosclerosis with
myeloid metaplasia/essential thrombocytopenia/refractory cytopenia with
multilineage dysplasia/myelodysplastic syndrome with 5q-syndrome/therapy-
related myelodysplastic syndrome
273.2 Alpha heavy chain disease/Franklin disease/gamma heavy chain disease
273.3 Waldenstrom macroglobulinemia
273.9 Unspecified disorder of immune mechanism (screen for potential 273.3 miscodes)
284.9 - 285.0 Refractory anemia
288.3 Hyperesinophilic syndrome
289.8 Acute myelofibrosis
V07.3 Other prophylactic chemotherapy (screen carefully for miscoded malignancies)
V07.8 Other specified prophylactic measure
V10 Personal history of malignancy (screen for subsequent primaries and/or subsequent
treatment)
V58.0 Admission for radiotherapy
V58.1 Admission for chemotherapy
V66.1 Convalescence following radiotherapy
V66.2 Convalescence following chemotherapy
V67.1 Radiation therapy followup
V67.2 Chemotherapy followup
V71.1 Observation for suspected malignant neoplasm
V76 Special screening for malignant neoplasm

*Carcinoma in situ of the cervix is not reportable; quality control procedures must be in place to make
sure if micro-invasion is present, the medical record is not coded to 233.1.
Appendix F: Examples of Central Cancer Registry State Laws

- New Jersey
- New York
- Pennsylvania
- Utah

CANCER REPORTING

New Jersey

CANCER REGISTRY STATUTE

26:2-104 Legislative findings and declaration

The Legislature hereby finds and declares:

i. That New Jersey is currently suffering from the highest overall mortality rates for cancer in the Nation;

ii. That certain forms of cancer are now believed to be attributable to environmental factors which, if controlled, can significantly reduce incidence in this State;

iii. That more complete and more precise statistical data are necessary to determine the correlations between cancer incidence and possible environmental factors and to evaluate cancer treatment and prevention measures that are currently in progress; and,

iv. That a cancer registry would thus provide a vital foundation for a concerted State effort to reduce the incidence of environmentally related cancer in this State.

L.1997, c266, s.1.

26:2-105 Establishment and maintenance; Inclusions

The Department of Health and Senior Services shall establish and maintain an up-to-date registry which shall include a record of cases of cancer and specified cases of tumorous or precancerous disease that occur in New Jersey, and such information concerning these cases as it shall deem necessary and appropriate in order to conduct thorough and complete epidemiologic surveys of cancer and cancer-related diseases in this State and to apply appropriate preventive and control measures.

L.1977, c.266, s.2; amended 2001, c.99, s.1.

26:2-106 Reports and submissions by health care providers; rules and regulations

v. The Commissioner of Health and Senior Services, in consultation with the Public Health Council, shall require the reporting of cases of cancer and other specified tumorous and precancerous diseases, and the submission of such specified additional information on reported cases or control populations as he deems necessary and appropriate for the recognition, prevention, cure or control of such diseases.
vi. Pursuant to subsection a. of this section, the Commissioner of Health and Senior Services is hereby authorized to adopt and promulgate, in the manner prescribed by the applicable provisions of the Administrative Procedure Act (P.L.1968,C.410;C.52:14B-1 et seq.), rules and regulations specifying the health care providers, individuals, and other organizations obliged to make the report and submissions required by subsection a. of this section, the related information to be included in such reports, and the methods for such reporting.

© All abstracting work performed by a health care facility in accordance with this section shall be performed by a certified tumor registrar.

(d) 1. The Department of Health and Senior Services shall contract out its registry services to health care facilities which lack adequate internal capabilities to report cases on a timely basis, as provided in the regulations adopted pursuant to this section. Such health care facilities shall reimburse the department for services rendered.

vii. If a health care facility fails to correct deficiencies in its reporting that are discovered on audit by the Department of Health and Senior Services within 30 days, the department will conduct the appropriate registrar activities and charge the facility for all costs related to its services.

viii. Health insurers and other third party health care payers providing health benefits plans to residents of the State shall report to the Department of Health and Senior Services cases of cancer of State residents based upon selection criteria and in a format specified by the department.

(f) 1. A health care facility, health care provider or health insurer that fails to comply with the provisions of this section shall be liable to a penalty of up to $500 per unreported cancer case.

ix. A health care facility that fails to report cases of cancer electronically, as required by regulation, within six months of the confirmed diagnosis shall be liable to a penalty not to exceed $1,000 per business day.

x. A penalty sued for under the provisions of this subsection shall be recovered by and in the name of the Department of Health and Senior Services and shall be dedicated to the cancer registry.

(g) All information reported to the Department of Health and Senior Services for inclusion in the cancer registry pursuant to this section shall be verified for accuracy by the department within six months of receiving the information and shall be incorporated in the registry. Aggregate or summary information, to include gender distribution, age groupings of cases, and cancer types, shall be made available to the public no later than six months after verification by the department. The department shall not make public any information reported to the department which discloses the identity of any person to whom the information relates.

L.1997, c.266, s.3; amended 1996, c.74, s.1; 2001, c.99, s.2.

26:2-107  Confidentiality of reports

The reports made pursuant to this act are to be used only by the State Department of Health and Senior Services and such other agencies as may be designated by the Commissioner of Health and Senior Services and shall not otherwise be divulged or made public so as to disclose the identity of any person to whom they relate; and to that end, such reports shall not be included under materials available to public inspection pursuant to P.L.1963,c73 (C.47:1A-1 et seq.).

L.1977, c.266, s.4; amended 2001, c.99, s.3

26:2-108  Non-liability for divulging confidential information

No individual or organization providing information to the Department of Health and Senior Services in accordance with this act shall be deemed to be, or be held liable for, divulging confidential information.

26:2-109  Inapplicability of act to compel individuals to submit to medical or health department examination or supervision

Nothing in this act shall be construed to compel any individual to submit to medical or health department examination or supervision.
CHAPTER 57A

CANCER REGISTRY

Authority

N.J.S.A. 26:2-104 et. Seq.

Source and Effective Date

R.1995 d.241, effective April 12, 2000,
See: 27 N.J.R. 629(a), 27 N.J.R. 1988(a),

Executive Order No. 66(1978) Expiration Date

Chapter 57A, Cancer Registry, expires on April 12, 2005

Chapter Historical Note


Pursuant to Executive Order No. 66(1978), Chapter 57A was readopted as R.1995 d.241. See: Source and Effective Date. See, also, section annotations.

CHAPTER TABLE OF CONTENTS

SUBCHAPTER 1. CANCER REGISTRY

8:57A-1.1 Reporting of cancer; general requirements
8:57A-1.2 Health care facility reporting
8:57A-1.3 Physician, dentist, and other health care provider reporting
8:57A-1.4 Clinical laboratory reporting
8:57A-1.5 Health care insurer reporting
8:57A-1.6 Supplemental information
8:57A-1.7 Access to information and records
8:57A-1.8 List of reportable diseases and conditions
8:57A-1.9 Audit, notice of violations, and enforcement actions
8:57A-1.10 Civil monetary penalties
8:57A-1.11 Effective date of enforcement action
8:57A-1.12 Failure to pay a penalty; remedies
8:57A-1.13 Hearings
8:57A-1.14 Settlement of enforcement actions

SUBCHAPTER 1. CANCER REGISTRY

8:57A-1.1 Reporting of cancer; general requirements

xi. Cases of cancer and other specified tumorous and precancerous diseases shall be reported to the New Jersey Department of Health and Senior Services. The reportable diseases and conditions shall be specified in a listing promulgated by the Commissioner of the New Jersey Department of Health and Senior Services, at N.J.A.C. 8:57A-1.8.

xii. All case reports shall be submitted within six months of the date of diagnosis or within three months of the date of discharge from the reporting facility, whichever is sooner.
xiii. ©Follow-up reports shall be submitted on each cancer case at least annually to confirm the patient’s vital status. These follow-up reports shall be required until the patient’s death.

Amended by R.1990 d.242, effective May 21, 1990.

Third party payers permitted to report cases to the Registry; machine readable submissions permitted.


See: 29 N.J.R. 2759(a), 30 N.J.R. 2903(b).
Rewrote the section.

8:57A-1.2 Health care facility reporting

xiv. The administrative officer of every health care facility shall report to the New Jersey Department of Health and Senior Services every case of cancer or other specified tumors and precancerous disease when it is initially diagnosed or when the patient is first admitted or treated for any reason in that facility. A report shall also be submitted for each subsequent primary cancer diagnosed in that individual.

xv. Health care facility means a facility as defined at N.J.S.A. 26:2H-1 et. Seq. and amendments thereto.

xvi. All abstracting work performed by a health care facility which diagnoses or treats 100 or more cancer cases per year shall be performed by a tumor registrar who is certified by the National Board for the Certification of Registrars, PO Box 15945-302, Lenexa, KA 66285-5945. The certified tumor registrar shall be either employed by the health care facility or employed by an abstract-coding service under contract by the health care facility.

xvii. The health care facility shall have until August 3, 2000 to comply with the provisions of (b) above.

xviii. The information to be reported shall:

1. Be submitted electronically in a standard format which is specified by the New Jersey Department of Health and Senior Services; and
2. Include patient identifying information, medical history, cancer treatment, and an annual report to confirm the patient’s vital status until the patient’s death.

xix. Health care facilities which lack adequate internal capabilities to report cases in accordance with the requirements of (b) and (c) above shall contract with the New Jersey Department of Health and Senior Services to provide abstracting services.

xx. The New Jersey Department of Health and Senior Services shall charge a fee to health care facilities for the provision of services set forth at (d) above. The fee shall be based upon the fair market value of services.

xxi. A health care facility which fails to comply with the provisions of this subchapter shall be liable for a penalty of up to $500.00 per unreported case of cancer or other specified tumorous and precancerous disease.

xxii. A health care facility which fails to report cases of cancer or other specified tumorous and precancerous diseases electronically shall be liable to a penalty not to exceed $1,000 per business day.

Recodified from N.J.A.C. 8:57A-1.1(b) and amended by R.1998 d.393, effective August 3, 1998.
See: 29 N.J.R. 2759(a), 30 N.J.R. 2903 (b).
Rewrote the section. Former N.J.A.C. 8:57A-1.2, Reportable list, was recodified to N.J.A.C. 8:57A-1.8.
**8:57A-1.3 Physician, dentist, and other health care provider reporting**

xxiii. Every physician, dentist, or other health care provider who diagnoses or provides treatment for cancer patients shall report to the New Jersey Department of Health and Senior Services an initial diagnosis of each case of cancer or other specified tumorous and precancerous disease not referred to or previously diagnosed in a health care facility in the State of New Jersey. A report shall also be submitted for each subsequent primary cancer diagnosed in that individual.

xxiv. The information to be reported shall:

xxv. Be submitted on forms specified by the New Jersey Department of Health and Senior Services; and

xxvi. Include patient identifying information, medical history, and cancer treatment.

xxvii. The physician, dentist, or other health care provider may submit the reports electronically in a standard format which is specified by the New Jersey Department of Health and Senior Services.

xxviii. A physician, dentist or other health care provider who fails to comply with the provisions of this subchapter shall be liable for a penalty of up to $500.00 per unreported case of cancer or other specified tumorous and precancerous disease.


See: 29 N.J.R. 2759 (a), 30 N.J.R. 2903 (b).
Rewrote the section.

**8:57A-1.4 Clinical laboratory reporting**

xxix. The director of every independent clinical laboratory shall report to the New Jersey Department of Health and Senior Services the results of examinations of tissue specimens and/or hematology examinations which are positive for the existence of cancer or other specified tumorous and precancerous disease not previously reported from that laboratory.

xxx. The information to be reported shall:

xxxi. Be submitted on forms specified by the New Jersey Department of Health and Senior Services; and

xxxii. Include all available patient identifying information and the name, address, and/or telephone number of the referring physician.

xxxiii. The director of the independent clinical laboratory may submit the reports electronically in a standard format which is specified by the New Jersey Department of Health and Senior Services.

xxxiv. An independent clinical laboratory which fails to comply with the provisions of this subchapter shall be liable for a penalty of up to $500.00 per unreported case of cancer or other specified tumorous and precancerous disease.

Recodified from N.J.A.C. 8:57A-1.1 (d) and amended by R.1998 d.393, effective August 3, 1998.

See: 29 N.J.R. 2759 (a), 30 N.J.R. 2903 (b).
Rewrote the section.

**8:57A-1.5 Health care insurer reporting**

xxv. Health care insurers and other third party health care payers providing benefit plans to residents of the State may report to the New Jersey Department of Health and Senior Services cases of cancer or other specified tumorous and precancerous diseases based upon selection criteria specified by the Cancer Registry.

xxvi. If reported, the information shall:

xxvii. Be submitted on forms specified by the New Jersey Department of Health and Senior Services; and

xxviii. Include patient identifying information, medical history, cancer treatment, and an annual report to confirm the patient’s vital status until the patient’s death.
xxxix. Health care insurers and other third party health care payers providing benefit plans to residents of the State may submit the reports electronically in a standard format which is specified by the New Jersey Department of Health and Senior Services.

Recodified from N.J.A.C. 8:57A-1.1(e) and amended by R.1998 d.393, effective August 3, 1998.
See: 29 N.J.R. 2759(a), 30 N.J.R. 2903(b).
Rewrote the section.

8:57A-1.6 Supplemental information

Information necessary to clarify medical or demographic data shall be supplied upon request of the New Jersey Department of Health and Senior Services. This supplemental information shall include, but not be limited to: copies of pathology and/or hematology reports, operative reports, treatment information, history and physical sections of the medical records, and discharge summaries.

See: 29 N.J.R. 2759(a), 30 N.J. R. 2903(b).
Rewrote the section.

8:57A1-7. Access to information and records

xl. Every health care facility, independent clinical laboratory, physician, dentist, or other health care provider who diagnoses or provides treatment for cancer patients and health care insurers and other third party health care payers providing benefit plans to residents of the State shall allow representatives of the New Jersey Department of Health and Senior Services to obtain information from all medical, pathological, and other pertinent records and logs related to cancer cases, as necessary for fulfilling the functions of the cancer registry program.

xli. Every health care facility, independent clinical laboratory, physician, dentist, or other health care provider who diagnoses or provides treatment for cancer patients and health care insurers and other third party health care payers providing benefit plans to residents of the State shall permit representatives of the New Jersey Department of Health and Senior Services access to information or provide necessary information on specified cancer patients and other patients specified by characteristics for research studies related to cancer etiology, prevention, and control which are conducted by the New Jersey Department of Health and Senior Services. These studies, shall have been approved by the Commissioner of the New Jersey Department of Health and Senior Services after appropriate review to assure protection of human subjects. This access or provision of information shall include patients who came under the care of the health care facility, physician, dentist, or other health care provider prior to November 18, 1977.

xlii. The reports made pursuant to this subchapter shall be used only by the New Jersey Department of Health and Senior Services and such other agencies as may be designated by the Commissioner of the New Jersey Department of Health and Senior Services. These reports shall not be otherwise divulged or made public. Such reports shall not be subject to public inspection and copying pursuant to the Right-to-Know Act, N.J.S.A. 47:1A-1 et seq.

xliii. No individual or organization providing information to the New Jersey Department of Health and Senior Services in accordance with this subchapter shall be deemed to be, or held liable for, divulging confidential information.

xliv. Any individual or organization which reveals or discloses any information or data in violation of above shall be the subject of penalties as permitted by law. All violations shall be reported to the appropriate professional licensing authorities and public financing programs.

xlv. Failures to permit access to information and records to representatives of the New Jersey Department of Health and Senior Services shall be cause for the imposition of penalties as permitted by law.

Recodified from N.J.A.C. 8:57A-1.1(i) and (j) and amended by R.1998 d.393, effective August 3, 1998.
See: 29 N.J.R. 2759(a), 30 N.J.R. 2903(b).
Rewrote the section.
STATE OF NEW YORK
PUBLIC HEALTH LAW

Section 1. Short title.
This act shall be known and may be cited as the “cancer research improvement act of 1997.”

Section 2. Section 2401 of the public health law is amended to read as follows:

Section 2401. Cancer, duty to report.

1. Every physician, dentist and other health care provider shall give notice immediately but not later than one hundred eighty days of every case of cancer or other malignant disease coming under his or her care, to the department, except as otherwise provided.

2. Whenever an examination of a tissue specimen in a laboratory discloses the existence of cancer or other malignant disease, the person in charge of such laboratory or the person making such examination shall immediately but not later than one hundred eighty days report the same together with all the facts in connection therewith to the department.

3. The person in charge of every cancer reporting facility shall immediately but not later than one hundred eighty days give notice of every case of cancer or malignant disease coming under the care of the institution to the department.

4. All abstracting work performed by a cancer reporting facility pursuant to the reporting provisions of this section shall be performed by a certified tumor registrar. Cancer reporting facilities may establish consortia to engage a certified tumor registrar to perform the reporting requirements of this section. A “certified tumor registrar” is an individual certified by a nationally recognized not-for-profit organization which certifies tumor registrars. The provisions of this subdivision shall not apply to any cancer reporting facility which renders services for one hundred or fewer cases of cancer and malignant disease per year as determined by the commissioner.

5. The department shall establish and update as necessary a manual designating which specific data elements shall be reported to the department pursuant to this section. The department shall make such manual available to every cancer reporting facility, physician, dentist and other health care provider required to comply with the provisions of this section.

6. The department shall establish and update as necessary a data dictionary to standardize information interpretation of data elements reported by cancer reporting facilities and other health care providers. The department shall make such dictionary available to every cancer reporting facility, physician, dentist and other health care provider required to comply with the provisions of this section.

7. The department shall, to the extent funds are made available, establish or contract for regional training programs to provide training to any cancer reporting facility, physician, dentist or other health care provider required to comply with the provisions of this section. Such regional training programs shall provide training relating to the specific data elements which must be reported pursuant to this section, the dictionary establish pursuant to this section, and any other subjects which are intended to ensure quality, timely and complete compliance with this section.
8. The department shall meet cancer registry goals established by a nationally recognized central cancer registry organization unless any such goal is contrary to any provision of law.

9. Where a cancer reporting facility fails to comply with the provisions of this section, the department may elect to perform registry services for such facility. Such cancer reporting facility shall reimburse the department for actual expenses incurred.

10. A physician, dentist, laboratory, cancer reporting facility or other health care provider which violates any provision of this section shall be subject to a civil penalty as provided in section twelve of this chapter.

11. The notices required by this section shall be upon forms supplied by the commissioner and shall contain such information as shall be required by the commissioner.

12. For the purpose of this section, a “cancer reporting facility” means a hospital as defined in article twenty-eight of this chapter, clinic or any organization certified pursuant to article forty-four of this chapter, or other similar public or private institution.

13. The commissioner shall have the power to promulgate any such rules and regulations as shall be necessary and proper to effectuate the purposes of this section.
Pennsylvania Cancer Registry State Law

PA.PL 1241 No. 224
Section 6. Cancer Registry

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.
Utah Cancer Registry State Law

Cancer Reporting Rule R384-100

R384. Health, Community Health Services, Chronic Disease.

R384-100. Cancer Reporting Rule

R384-100-1. Purpose Statement
(1) The Cancer Reporting Rule is adopted under authority of sections 26-1-30 and 26-5-3.
(2) Cancers constitute a leading cause of morbidity and mortality in Utah and, therefore, pose an important risk to the public health. Through the routine reporting of cancer cases, trends in cancer incidence and mortality can be monitored and prevention and control measures evaluated.
(3) Cancer records are managed by the Utah Cancer Registry (Registry) on behalf of the Utah Department of Health. This Cancer Reporting Rule is adopted to specify the reporting requirements for cases of cancer to the registry. The Utah Department of Health retains ownership and all rights to the records.

R384-100-2. Definitions
As used in this rule:
(1) “Cancer” means all in-situ (with the exception of in-situ cervical cancers) or malignant neoplasms diagnosed by histology, radiology, laboratory testing, clinical observation, autopsy or suggestible by cytology, but excluding basal cell and squamous cell carcinoma of the skin unless occurring in the genital sites such as the vagina, clitoris, vulva, prepuce, penis and scrotum.
(2) “Follow-up data” includes date last seen or date of death, status of disease, date of first recurrence, type of recurrence, distant site(s) of first recurrence, and the name of the physician who is following the case.
(3) “Health care provider” includes any person who renders health care or professional services such as a physician, physician assistant, nurse practitioner, registered nurse, licensed practical nurse, dentist, optometrist, pediatric physician, osteopathic physician, osteopathic physician and surgeon, or others rendering patient care.
(4) “Registrar” means a person who:
   (a) is employed as a registrar and who has attended a cancer registrar training program;
   (b) has two years of experience in medical record discharge analysis, coding, and abstracting, and has successfully completed a course in anatomy, physiology, and medical terminology; or
   (c) has successfully passed the Certified Tumor Registrar examination offered by the National Cancer Registrars’ Association.
(5) “Reportable benign tumor” means any noncancerous neoplasm occurring in the brain.

R384-100-3. Reportable Cases.
Each case of cancer or reportable benign tumor, as described in R384-100-2, that is diagnosed or treated in Utah shall be reported to the Utah Cancer Registry, 546 Chipeta Way; Suite 410; Salt Lake City, Utah 84108, telephone number 801-581-8407, FAX number 801-581-4560.
Each report of cancer or reportable benign tumor shall include information on report forms provided by the Registry. These reports shall be made in the format prescribed by the Registry and shall include items such as the name and address of the patient, medical history, environmental factors, date and method of diagnosis, primary site, stage of disease, tissue diagnosis, laboratory data, methods of treatment, recurrence and follow-up data, and physician names.

R384-100-5. Agencies or Individuals Required to Report Cases.
(1) All hospitals, radiation therapy centers, pathology laboratories licensed to provide services in the state, nursing homes, and other facilities and health care providers involved in the diagnosis or treatment of cancer patients shall report or provide information related to a cancer or reportable benign tumor to the Registry.
(2) Procedures for reporting:
   (a) Hospital employed registrars shall report hospital cases.
   (b) Registrars employed by radiation therapy centers shall report center cases.
   (c) Pending implementation of electronic reporting by pathology laboratories, pathology laboratories shall allow the Registry to identify reportable cases and extract the required information during routine visits to pathology laboratories.
   (d) If a health care provider diagnoses a reportable case but does not send a tissue specimen to a pathology laboratory or arrange for treatment of the case at a hospital or radiation therapy center, then the health care provider must report the case to the Registry.
   (e) If the Registry has not received complete information on a reportable case from routine reporting sources (hospitals, radiation therapy centers, pathology laboratories), the Registry may contact health care providers and require them to complete a report form.

R384-100-6. Time Requirements.
(1) New Cases:
   (a) Hospitals and radiation therapy facilities shall submit reports to the Registry within six months of the date of diagnosis.
   (b) Other facilities and health care providers shall submit reportable data to the Registry upon request.
(2) Follow-up Data:
   (a) Hospitals and radiation therapy centers shall submit annual follow-up data to the Registry within 13 months of the date the patient was last contacted by hospital or facility personnel.
   (b) Physicians shall submit follow-up data to the Registry upon request.

R384-100-7. Reporting Format.
Reports shall be submitted in the standard format designated by the Registry. Report forms can be obtained by contacting the Registry.

Records maintained by hospitals, pathology laboratories, cancer clinics, and physicians are subject to review by Registry personnel acting on behalf of the Department of Health to assure the completeness and accuracy of reported data.
R384-100-9. Confidentiality of Reports.
All reports required by this rule are confidential under the provisions of Title 25, Chapter 3 and are not open to inspection except as allowed by Title 26, Chapter 3. The Registry shall maintain all reports according to the provisions of Title 26, Chapter 3.

R384-100-10. Penalties.
Enforcement provisions and penalties for the violation or for the enforcement of public health rules, including this Cancer Reporting Rule, are prescribed under Section 26-23-6 and are punishable as a class B misdemeanor on the first offense, a class A misdemeanor on the second offense or by civil money penalty of up to $5,000 for each violation.

KEY: cancer, reporting requirements and procedures
1999
26-1-30
26-5-3
Appendix G: Example of Central Cancer Registry Nonreportable List

Nonreportable Conditions

• Precancerous Conditions or Benign Tumors

Patients with precancerous conditions or benign tumors are not reportable. Examples of such diagnoses include atypical adenoma or benign brain tumors.

• Skin Cancers

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).

ICD-O codes C44.0-C44.9 include skin of the lip, eyelid, external ear, face, nose, scalp, neck, trunk, perineum, (peri) anus, umbilicus, upper and lower limbs, shoulders, hips, and skin around ostomy sites.

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

• Carcinoma In Situ of the Cervix

The diagnosis carcinoma in situ of the cervix (CIS) is not reportable.

• Intraepithelial Neoplasia

Patients with the following diagnoses of intraepithelial neoplasia are not reportable:

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

• Low Malignant Potential/Borderline Malignancy

Diagnoses qualified by the phrases borderline malignancy or low malignant potential are not reportable except when referring to cystadenomas or tumors primary to the ovary or peritoneum diagnosed prior to January 1, 2001.
• **Consult Only Records**

Patients seen in consultation only are not reportable. A consult may be done to confirm a diagnosis or treatment plan. The reporting institution may provide services not available at the diagnosing or treatment facility such as computerized tomography (CT) scans or magnetic resonance imaging (MRI) scans.

• **Terms That Do Not Constitute a Diagnosis**

Do not interpret the following terms as a diagnosis of malignancy. Do not report patients who have a final diagnosis consisting only of these terms without additional information to support reportability.

- cannot be ruled out
- potentially malignant
- suggests
- equivocal
- questionable
- worrisome
- possible
- rule out

*Example:* If the final diagnosis is reported as possible carcinoma of the breast, the case is not reportable.

*Note:* If a phrase such as “strongly suggestive” or “highly worrisome” is used, disregard the modifier (“-ly”) and refer to the guidelines above regarding the primary term.

• **Slide Reviews**

Records in which slides are sent to your hospital’s pathologist for a second opinion are encouraged to be reported, but are not required. Because the slide was already read by another pathologist, the facility requesting the slide review is required to report the final diagnosis as determined after the slide review.

• **Transient Care**

Patients receiving transient care at the reporting institution to prevent interruption of the first course of treatment are not reportable. The patient may be vacationing or visiting in the area, or equipment failure at the primary treating institution may require the patient to temporarily receive treatment elsewhere.

• **History Of**

Patients with a history of malignancy who are clinically free of disease are not reportable. If, however, the patient has actually received cancer-directed or non cancer-directed treatment during this hospital encounter, the record must be reported.
• **Recurrence**

Recurrence is defined as the same cancer arising in or from the same primary site where it appeared earlier and is not considered a new primary cancer by the physician. Do not report a recurrent diagnosis when you previously reported it.

*Exception:* If an in situ tumor is followed by an invasive cancer in the same site more than 2 months apart, report as two primaries even if stated to be a recurrence. The invasive primary should be reported with the date of the invasive diagnosis.

• **Readmitted Patients**

If a patient is readmitted and new or additional metastatic sites are diagnosed or documented, the record is not reportable provided it has already been reported for the original primary site. Records of readmitted patients must be reviewed to determine if a new primary site has been diagnosed. Each new primary must be reported separately.

• **Metastatic Sites**

Do not report the metastatic or secondary sites of a malignant neoplasm; however, check to make sure the primary site was previously reported. A diagnosis of metastatic cancer with an unknown primary site not previously reported should be submitted with the primary site documented or coded as unknown.

• **Special Units**

Patients admitted to a skilled nursing unit or other separately licensed unit are encouraged to be reported but are not required. These patients are either discharged from an acute care hospital unit and readmitted to a separately licensed unit or are admitted directly to the separately licensed unit.

• **Terminal Supportive Care**

Patients admitted for terminal supportive care only are not reportable.

• **Admitted for an Unrelated Medical Condition**

If a patient with active cancer is admitted for an unrelated medical condition (for example: motor vehicle accident) and does not receive any cancer treatment, the case is not reportable.

• **Nonreportable Conditions Effective January 1, 2001**

The following are terms that are no longer reportable beginning with cases diagnosed on or after January 1, 2001:

- Atypical proliferating serous tumor
- Atypical proliferative papillary serous tumor
- Atypical proliferative mucinous tumor
- Mucinous cystadenoma, borderline malignancy
- Mucinous tumor, NOS, of low malignant potential
Mucinous cystic tumor of borderline malignancy
Papillary cystadenoma, borderline malignancy
Papillary mucinous cystadenoma, borderline malignancy
Papillary mucinous tumor of low malignant potential
Papillary pseudomucinous cystadenoma, borderline malignancy
Papillary serous cystadenoma, borderline malignancy
Papillary serous tumor of low malignant potential
Pseudomucinous cystadenoma, borderline malignancy
Serous papillary cystic tumor of borderline malignancy
Serous tumor, NOS, of low malignant potential
Serous cystadenoma, borderline malignancy.
Appendix H: Academic Letter Interpreting HIPAA;
Legal Letter Interpreting HIPAA

July 13, 2001

Holly L. Howe, PhD
Executive Director
North American Association of Central Cancer Registries
2121 West White Oaks Dr, Suite C
Springfield, Illinois 62704

Re: Disclosure of Protected Health Information to Cancer Registries Under Federal Health Information Privacy Protections Pursuant to the Health Insurance Portability and Accountability Act of 1996 (HIPAA)

Dear Dr. Howe:

Thank you for this opportunity to address on behalf of the North American Association of Central Cancer Registries (NAACCR) a prevailing, legal issue that has arisen pursuant to the new federal health information privacy standards developed by the Department of Health and Human Services (DHHS) with Congressional authorization under the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

This issue may be succinctly stated as follows: Do the new federal health information privacy regulations limit the disclosure of individually-identifiable health information (namely cancer data) by medical providers and others to cancer registries for public health uses? For the reasons set forth below, I conclude that the HIPAA privacy regulations do not substantially limit these disclosures unless the recipient cancer registry is not a public health authority (as defined below). In fact, the HIPAA privacy regulations encourage and support the disclosure of individually-identifiable cancer data without specific, informed consent for public health purposes.

After Congress failed to meet a self-imposed deadline under HIPAA to enact a relevant privacy statute, DHHS assumed authority under the Act to develop regulations to protect the privacy of individually-identifiable health information. The regulations were finally approved by
President Bush on April 12, 2001. The official, effective date of the regulations is April 14, 2001. Covered entities (discussed below) have two (2) years to fully comply (or by April 14, 2003), except for small health plans, who have until April 14, 2004 to comply.

The HIPAA privacy regulations set forth privacy rules for the acquisition, use, storage, and disclosure of individually-identifiable health information (a.k.a. "protected health information") in paper or electronic form. Protected health information includes individually-identifiable information relating to cancer diagnoses, tests, and treatments. If health information is non-identifiable (i.e., it cannot be identified to any individual), it is not covered by the HIPAA privacy regulations principally because the use and exchange of such data raises little or no individual privacy concerns.

The regulations govern the acts of covered entities. Covered entities include health care providers (e.g. hospitals, physicians, laboratories) who transmit any health information in electronic form pursuant to certain financial and administrative transactions. Most hospitals and physicians typically rely on some form of electronic billing or information exchange, and thus fall under the requirements of the Act.

Concerning disclosures, the HIPAA privacy regulations set forth a standard rule: protected health information shall not be disclosed without the written, informed consent of the individual who is the subject of the information. However, DHHS recognizes several exceptions to this general rule to allow disclosures for various communal goods, including disclosures made for public health purposes.

The "public health" exemption states that a covered entity may disclose protected health information without specific, individual informed consent to a "public health authority that is authorized by law to collect and receive such information for the purpose of preventing and controlling disease, injury, or disability, including . . . reporting of disease . . . and the conduct of public health surveillance . . . ." Provided that a cancer registry fits the definition of a public health authority, the registries' acquisition of identifiable cancer data for surveillance or other

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1 Statement by DHHS Secretary Tommy G. Thompson Regarding the Patient Privacy Rule. April 12, 2001.


3 45 C.F.R. § 160.103 (defining health care provider in reference to two other acts as well as to include “any person or organization who furnishes, bills, or is paid for health care in the normal course of business”).

4 45 C.F.R. § 164.104.

legitimate public health purposes is protected under the exemption, and thus does not require individual informed consent.

A public health authority is defined as an:

agency or authority of the United States, a State, a territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency . . . that is responsible for public health matters as part of its official mandate.  

This definition clearly applies to central or regional cancer or tumor registries operated by a state or local department of health, or as a freestanding, state-supported agency. A public health authority also includes some private sector entities that perform public health functions (like cancer surveillance) pursuant to a grant of authority or contract with a governmental public health agency.

Since most cancer or tumor registries would be considered public health authorities, covered entities under HIPAA may disclose protected health information to these registries without the individual informed consent of each patient pursuant to the "public health" exemption to HIPAA general disclosure rule.

However, any non-governmental entity that performs services similar to government-supported cancer registries, but is not acting under a grant of authority from or does not contract with a public agency, would likely not come under the exemption. This entity must follow the regulation’s requirements relating to patient consent, authorization, and opportunity to object or agree before disclosure by a covered entity is permitted.

This conclusion is affirmed by the pre-emption provisions in the HIPAA privacy regulations. The privacy regulations expressly do not pre-empt (or override) state law that “provides for the reporting of disease or injury . . . or for the conduct of public health surveillance [or] investigation . . .” Thus, state law that permits covered entities to disclose identifiable information to cancer registries without individual informed consent remains intact. This further supports a cancer registry’s ability to collect protected health information without the patient’s informed consent where state law allows the registry to do so.

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7 See DHHS, Section 164.512(b) -- Uses and Disclosures for Public Health Activities, in Section-by-Section Discussion of Comments, Preamble Part III of Standards of Privacy of Individually Identifiable Information (June 28, 2001) <http://aspe.hhs.gov/admnsimp/final/PvcPre03.htm> (responding to the first comment listed).

While HIPAA does not limit disclosures of protected health information to cancer registries, the Act requires covered entities to log these and many other disclosures.\textsuperscript{9} This minimal requirement preserves the individual’s right to review an accounting of disclosures of their health information over a certain period of time (generally six years).

I hope that this opinion letter clarifies the effect of the new HIPAA privacy regulations concerning the disclosure of individually-identifiable health information to cancer registries from hospitals, physicians, laboratories, and other medical providers. In summary, the regulations allow for these disclosures without specific, informed consent provided the cancer registry is a public health authority. Please let me know your questions, comments, or concerns related to this opinion. You may reach me via email at jhodge@jhspsh.edu, or via phone, (410) 955-7624.

With best wishes,

James G. Hodge, Jr., J.D., L.L.M.
Adjunct Professor of Law, Georgetown University Law Center
Assistant Scientist, the Johns Hopkins School of Public Health

\textsuperscript{9} 45 C.F.R. § 164.528 (2001).
August 15, 2001

Holly L. Howe, PhD.
Executive Director
North American Association
of Central Cancer Registries
2121 W. White Oaks Dr., Suite C
Springfield, Illinois 62708

Re: The Federal Privacy Rule's Application to Central Cancer Registries

Dear Dr. Howe:

At your request, we have reviewed the letter dated July 13, 2001, which you received from Professor James Hodge of the Georgetown University Law Center. As discussed by Professor Hodge, federal regulations, entitled Standards for Privacy of Individually Identifiable Health Information (the "Privacy Rule"), restrict the use and disclosure of health information by health care providers, health plans, and health care clearinghouses. After reviewing the relevant regulations, Professor Hodge concluded that the Privacy Rule does not restrict the disclosure of patient information by a health care provider to a central cancer registry so long as the central cancer registry is a "public health authority." We agree with that conclusion.

On July 6, 2001, the U.S. Department of Health and Human Services ("DHHS") issued its Guidance on the Privacy Rule and on the issue addressed by Professor Hodge. DHHS concluded that disclosures to public health authorities are permitted under the Privacy Rule, and among various Questions and Answers, stated:

1. 45 C.F.R. § 164.500 et. seq.

2. Guidance on Standards for Privacy of Individually Identifiable Health Information, issued by the U.S. Department of Health and Human Services, at pg. 54 (July 6, 2001).
Q: Must a health care provider or other covered entity obtain permission from a patient prior to notifying public health authorities of the occurrence of a reportable disease?

A: No. All states have laws that require providers to report cases of specific diseases to public health officials. The Privacy Rule allows disclosures that are required by law. Furthermore, disclosures to public health authorities that are authorized by law to collect or receive information for public health purposes are also permissible under the Privacy Rule. In order to do their job of protecting the health of the public, it is frequently necessary for public health officials to obtain information about the persons affected by a disease. In some cases they may need to contact those affected in order to determine the cause of the disease to allow for actions to prevent further illness.

The Privacy Rule continues to allow for the existing practice of sharing [protected health information] with public health authorities that are authorized by law to collect or receive such information to aid them in their mission of protecting the health of the public. Examples of such activities include those directed at the reporting of disease or injury, reporting deaths and births, investigating the occurrence and cause of injury and disease, and monitoring adverse outcomes related to food, drugs, biological products and dietary supplements. (emphasis added).

As explained by DHHS in its Guidance, the Privacy Rule allows disclosure of information to public health authorities. With respect to the disclosure of information to central cancer registries, and as noted by Professor Hodge, whether the Privacy Rule restricts the disclosure of information depends on whether each central cancer registry falls within the definition of a "public health authority." A public health authority is defined as:

an agency or authority of the United States, a State or territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency...that is responsible for public health matters as part of the official mandate. 3 (emphasis added).

3 45 C.F.R. §164.501
Since state cancer registries come within this definition, the Privacy Rule does not restrict disclosure of patient information to them. For the exemption to apply to a non-governmental registry, however, the registry must operate pursuant to a contract with a public agency or under a grant of authority from a public agency.

Should you have any further questions regarding this issue, please advise.

Very truly yours,

Jeffery M. Wilday

JMW:ddh
Appendix I: Example of Central Cancer Registry
Casefinding Procedures and List

• Illinois

Illinois State Cancer Registry (ISCR)

All reporting facilities are responsible for complete casefinding. A master index/suspense file should be maintained by all nonregistry facilities (reviewed in Section II). Procedures for implementing casefinding must be adopted by each reporting facility, and at a minimum, should include sources as outlined below.

1. CASEFINDING PROCEDURES

To ensure complete case ascertainment, the following sources should be reviewed as they apply:

   a) Medical record disease index (if available)
   b) Pathology/Cytology reports
   c) Outpatient clinic logs, including surgery logs
   d) Radiation therapy clinic logs and appointment books
   e) Oncology clinic logs and appointment books
   f) Diagnostic x-rays
   g) Nuclear medicine reports
   h) Immunotherapy
   i) CPT coding index
   j) Autopsy reports.

A) Medical Record Disease Index

The following list is intended to assist in reportable neoplasm casefinding activities that are performed in casefinding sources that use ICD-9-CM codes to codify the diagnosis. Codes and/or terms that have new malignant behavior codes in ICD-O-3 are underlined, and the ICD-O-3 code is placed in parentheses following the terms. This information is taken directly from the SEER program Web Site, Y2001 Casefinding List.

<table>
<thead>
<tr>
<th>ICD-9-CM Codes</th>
<th>Diagnosis (in preferred ICD-O-3 terminology)</th>
</tr>
</thead>
<tbody>
<tr>
<td>042</td>
<td>AIDS (review cases for AIDS-related malignancies)</td>
</tr>
<tr>
<td>140.0 - 208.9</td>
<td>Malignant neoplasms</td>
</tr>
<tr>
<td>203.1</td>
<td>Plasma cell leukemia (9733/3)</td>
</tr>
<tr>
<td>230.0 - 234.9</td>
<td>Carcinoma in situ</td>
</tr>
<tr>
<td>235.0 - 238.9</td>
<td>Neoplasms of Uncertain Behavior</td>
</tr>
<tr>
<td>238.4</td>
<td>Polycythemia vera (9950/3)</td>
</tr>
<tr>
<td>238.6</td>
<td>Solitary plasmacytoma (9734/3)</td>
</tr>
<tr>
<td>ICD-9-CM Codes</td>
<td>Diagnosis (in preferred ICD-O-3 terminology)</td>
</tr>
<tr>
<td>---------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>238.7</td>
<td>Chronic myeloproliferative disease (9960/3)</td>
</tr>
<tr>
<td>238.7</td>
<td>Myelosclerosis with myeloid metaplasia (9961/3)</td>
</tr>
<tr>
<td>238.7</td>
<td>Essential thrombocytremia (99623/3)</td>
</tr>
<tr>
<td>238.7</td>
<td>Refractory cytopenia with multilineage dysplasia (9985/3)</td>
</tr>
<tr>
<td>238.7</td>
<td>Myelodysplastic syndrome with 5q- syndrome (9986/3)</td>
</tr>
<tr>
<td>238.7</td>
<td>Therapy related myelodysplastic syndrome (9987/3)</td>
</tr>
<tr>
<td>239.0 - 239.9</td>
<td>Neoplasms of unspecified behavior</td>
</tr>
<tr>
<td>273.2</td>
<td>Gamma heavy chain disease; Franklin’s disease</td>
</tr>
<tr>
<td>273.3</td>
<td>Waldenstrom’s macroglobulinemia</td>
</tr>
<tr>
<td>273.9</td>
<td>Unspecified disorder of immune mechanism (screen for potential 273.3 miscodes)</td>
</tr>
<tr>
<td>284.9</td>
<td>Refractory anemia (9980/3)</td>
</tr>
<tr>
<td>285.0</td>
<td>Refractory anemia with ringed sideroblasts (9982/3)</td>
</tr>
<tr>
<td>285.0</td>
<td>Refractory anemia with excess blasts (9983/3)</td>
</tr>
<tr>
<td>285.0</td>
<td>Refractory anemia with excess blasts in transformation (9984/3)</td>
</tr>
<tr>
<td>289.8</td>
<td>Acute myelofibrosis</td>
</tr>
<tr>
<td>V07.3</td>
<td>Other prophylactic chemotherapy (screen carefully for miscoded malignancies)</td>
</tr>
<tr>
<td>V07.8</td>
<td>Other specified prophylactic measures</td>
</tr>
<tr>
<td>V10.0-V10.9</td>
<td>Personal history of malignant neoplasm (review these for recurrences, subsequent primaries, and/or subsequent treatment)</td>
</tr>
<tr>
<td>V58.0</td>
<td>Admission for radiotherapy</td>
</tr>
<tr>
<td>V58.1</td>
<td>Admission for chemotherapy</td>
</tr>
<tr>
<td>V66.1</td>
<td>Convalescence following radiotherapy</td>
</tr>
<tr>
<td>V66.2</td>
<td>Convalescence following chemotherapy</td>
</tr>
<tr>
<td>V67.1</td>
<td>Radiation therapy followup</td>
</tr>
<tr>
<td>V67.2</td>
<td>Chemotherapy followup</td>
</tr>
<tr>
<td>V71.1</td>
<td>Observation for suspected malignant neoplasm</td>
</tr>
<tr>
<td>V76 – V76.9</td>
<td>Special screening for malignant neoplasm</td>
</tr>
</tbody>
</table>
B) Pathology/Cytology Reports

All pathology reports should be reviewed for reportable neoplasms. These include reports on inpatient and outpatient surgical resections and biopsy specimens, bone marrow biopsies, cytology specimens, and autopsies. A list of identified cases should be made and copies of the pathology reports kept on all patients with a positive morphologic diagnosis of cancer. All “possible” diagnoses also should be noted so that the entire record of the patient can be reviewed to determine reportability. Reporting facilities also are being asked to report “reference only” cases of melanoma and prostate cancer.

C) Medical Records Chart Review

Some Medical Record Departments have personnel who see all patient records on discharge and can identify cancer cases for the cancer registry or reporting abstractor. Such identification is done by listing cases, holding the cases for review by the Registrar/Cancer Incidence Recorder, or marking the record for routing to the Registrar/Cancer Incidence Recorder. In some facilities, copies of the discharge summaries of patients with cancer are given to the cancer registry.
Appendix J: Example of Central Cancer Registry Procedures for Evaluating Inconsistencies Between Data Items; Example of Discrepancy Letter

- Illinois

Illinois State Cancer Registry

Reconciling Site/Morphology Discrepancies Generated From EDITS

Edit-Primary Site, Morphology-Impossible (SEER IF38)

Review the site/histology text on the abstract or documentation provided by the reporting facility. If the information does not support a change to the site or histology, refer to the NAACCR Standard Data Edits Volume IV, error correction help in the Primary Site, Morphology-Impossible (SEER IF38) specific guidelines to change either the site or histology. These guidelines provide suggestions for analyzing an error. If the abstract does not include text or supporting documentation is not provided, a discrepancy letter is sent to all reporting facilities.

Edit-Primary Site, Morphology-Type Check (SEER IF25)

All site/histology type check edits that are generated are to be verified by using the text provided on the abstract. Discrepancy letters requesting supporting documentation or verification of the site/histology combination are sent to all reporting facilities, except registry hospitals.
Facility #:

To: Cancer Registrar, Cancer Incidence Recorder

The computer edit review of a batch that you have submitted reveals a potential discrepancy. Would you please verify the information identified in this letter by submitting the appropriate documentation or correction.

Should the discrepancy involve primary site and/or morphology, we would appreciate a copy of pertinent pathology reports, operative reports, discharge summary and history, and physical examination reports that support the diagnosis.

Please return the requested information to our attention within 3 weeks.

Illinois State Cancer Registry
605 West Jefferson
Springfield, Illinois 62761
Attn: Teri (217-785-7125)

Patient Name:

Med Rec # or Acc #:

Discrepancy:

Your facility submitted:
Other facility submitted:

Response:

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
Appendix K: Example of Central Cancer Registry
Case Acceptance Policies

- Florida

Florida Cancer Data System

Data Submission: Acceptance/Rejection Policy

All cases must be transmitted to the Florida Cancer Data System (FCDS) via the Internet in accordance with FCDS Data Submission Policies. An 85 percent accuracy rate has been set as the standard for data submission.

Data Acceptance Policy
Data transmitted to FCDS and processed with an error rate less than or equal to 15 percent will be accepted. The cases that pass edit check will move into the FCDS master file; the cases that fail edit check will reside in the pending file awaiting resolution. A letter stating that the data was processed and accepted, along with the edit reports (Discrepancy Analysis Journal and Edit Check Discrepancy Journal), will be mailed to the reporting facility. The reporting facility must make corrections to each case that appears on the Edit Check Discrepancy Journal and then return the hardcopy corrections to FCDS within 3 weeks of receipt of the Data Acceptance Letter.

Data Rejection Policy
Data transmitted to FCDS and processed with an error rate greater than 15 percent will be rejected. A letter stating that the data was processed and rejected, along with the edit reports (Discrepancy Analysis Journal and Edit Check Discrepancy Journal), will be mailed to the reporting facility. The reporting facility must make the corrections to each case that appears on the Edit Check Discrepancy Journal in the reporting facility database. FCDS will not accept hardcopy corrections. The facility must resubmit all the cases to FCDS once all the corrections have been made in the facility database. FCDS requires that the data be resubmitted within 3 weeks of receipt of the Data Rejection Letter.

FCDS will not process any additional data from any facility until all cases pending edit corrections from previous submissions are resolved and no cases reside in the FCDS pending file.