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CT **CANCER REGISTRY PERSONNEL, OFFICE SPACE, AND EQUIPMENT**

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INTRODUCTION

Budgets are key components of registry operations. A budget is a detailed plan showing how resources will be acquired and used during a specific time period. It represents a plan for the future, expressed in formal, measurable terms.

To be useful, a budget must be prepared in sufficient detail to inform all levels of registry management of the exact expectations. Budgetary control is the use of the budget to regulate and guide activities. Three common types of common budgets include traditional, based on past experience plus forecasts for inflation and other variables; zero-based, a resource allocation method that requires budget makers to examine every expenditure during each budget period and justify the expenditure in light of current needs; and program planning, built around identifiable projects that must be accomplished. Registry budgets are program-planning budgets.

Adequate funding for the registry can be very difficult to obtain. As with many projects, the allocation can determine the scope of work rather than the other way around. Start-up costs for the establishment of a new registry are different than those needed to maintain an established registry. Start-up costs may diminish after the second year of operation, especially when equipment has been acquired.

BUDGET OBJECTIVES

Registry budget objectives consist of the following:

- A basic plan through which expenditures and revenues from all sources can be forecasted and displayed
- A statement on the objectives of the registry expressed in quantitative terms
- An estimate of future planning needs arranged in an organized manner, covering some or all of the registry activities for a defined period of time
- Pre-established standards against which actual operations are compared
- Motivation of all individuals by creating a climate of cost consciousness

OPERATIONAL BUDGET

Operational budgets are used to allocate and control resources in a manner consistent with the registry. Conversely, additional costs will be phased in as the registry grows to a more complex system.

There are three major expense components of the central registry's budget that must be given particular attention: personnel, travel, and data processing costs. There must be an adequate number of well-trained personnel in the registry, and the salaries must be competitive. Excessive personnel turnover within the registry will be counterproductive and can cause delays in reporting. Ordinarily, the single largest expense in a registry budget is personnel. Personnel expenses can be difficult to project. Employees have different anniversary dates and different salary increases. Typically an average annual increase of 3% to 5%.

Data processing funds must be sufficient to achieve the registry's intent. Whether the data processing functions are performed in-house or contracted, data must be entered, edited, aggregated, and reported.

BUDGET CYCLE

The budget cycle includes five steps: preparation, presentation, adoption, administration, and budget monitoring.

1. Preparation of the budget includes identifying registry revenue and operating and capital expenses for the budget period.
2. Presentation of the budget, including projections and expense justification, is made to individuals who must approve the budget.
3. The budget is adopted when all necessary approvals of the budget are obtained.
4. Administration, or execution, of the budget occurs in accordance with the budget plan.
5. Monitoring of budget performance may involve the use of control documents to track revenues and expenditures in relation to the budget.

Reports designed for use in preparing and monitoring the budget typically include performance reports that depict the budget, actual income and expenditures, and the variance between them. These reports often show the current reporting period and the year-to-date figures. Year-to-date cumulative figures are often more significant than monthly figures when comparing budgeted and actual income and expenses. For example, the year-to-date actual expenses tend to smooth out some of the variances caused by "one time only" events, such as attendance at a professional meeting.
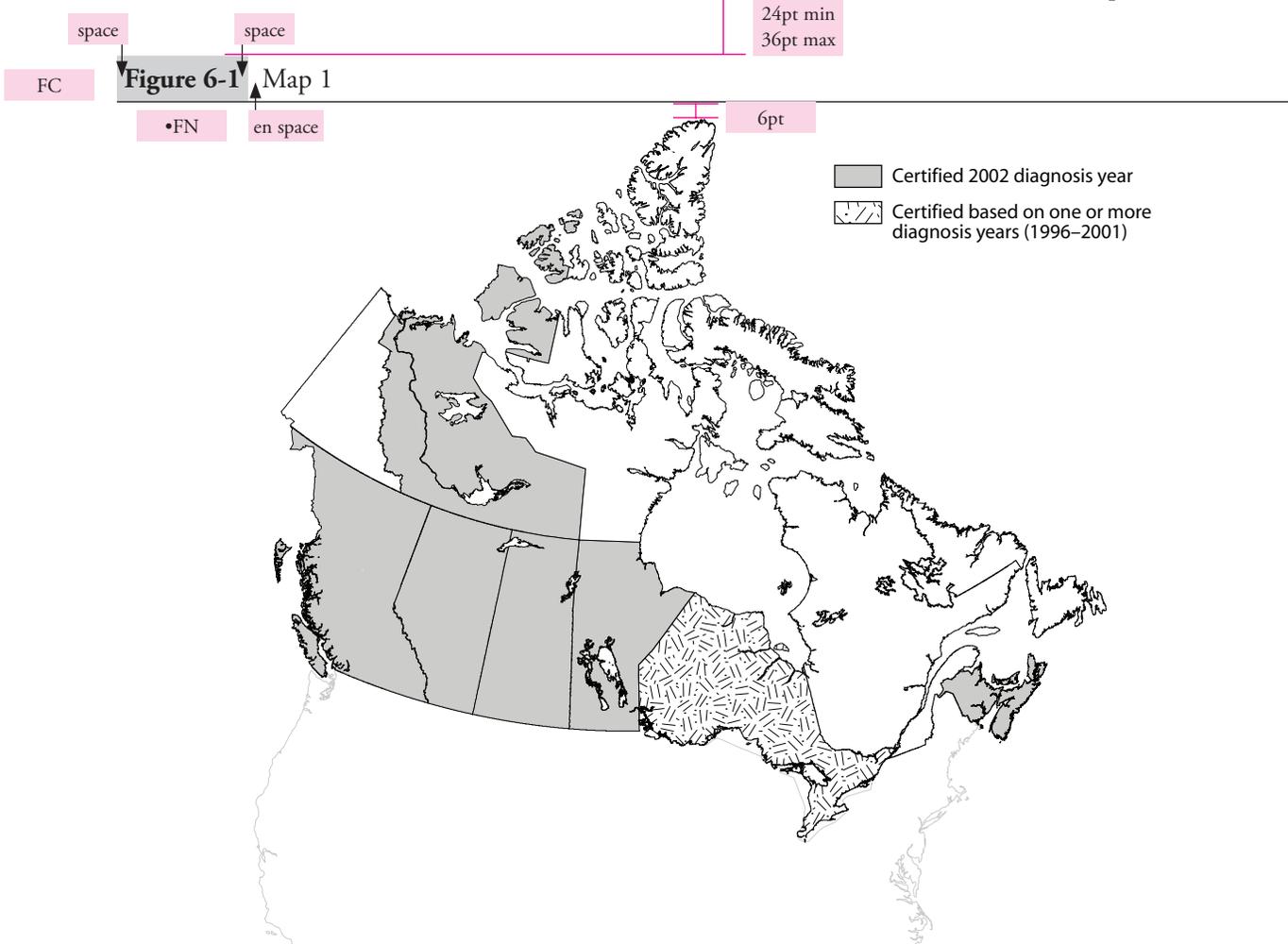
Variances can be both favorable and unfavorable. Actual expenditure in excess of budget is an unfavorable variance. Favorable and unfavorable variances refer to the impact on the registry rather than the magnitude or direction of the variance. While the terms positive and negative are sometimes used, this can be confusing because a negative expense variance is favorable to the registry.
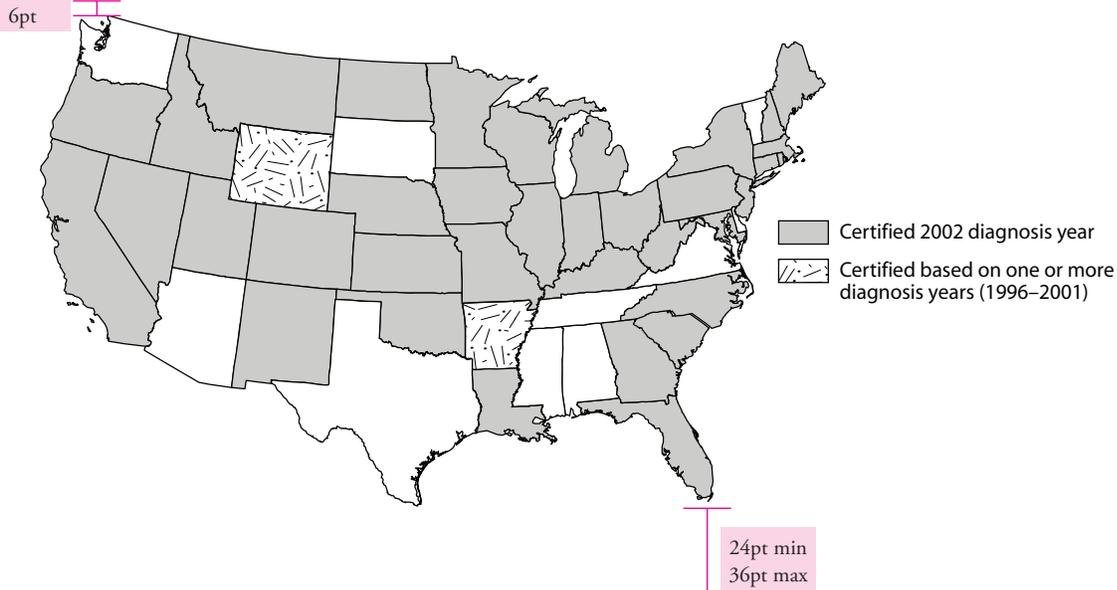
CAPITAL BUDGET

Capital budgets are used for long-term investments. The capital budget is prepared concurrently with the operating budget and addresses large-dollar purchases, as defined by budget policies. These items typically have a useful life in excess of one fiscal year, making them long-term assets, and a dollar value in excess of a predetermined amount, often $500 or $1,000. Computer equipment is an example of a capital investment item. Computer software has a limited useful life and is often included in the operational budget.

The purchasing department or a grant and contracts department's funding restrictions may control the acquisition of long-term assets. Specific guidelines and policies may require the use of specific vendors to provide certain types of equipment. Some funding sources require the acquisition of assets through the request for proposal (RFP) process. The RFP process is a control mechanism designed to eliminate bias and to ensure competitive pricing in the acquisition of goods and services.

Some long-term assets, such as equipment and furniture, wear out over time and must be replaced. Accumulated depreciation represents that portion of an asset's life, expressed in dollar terms, that has been consumed over time in generating revenue. Depreciation is calculated by dividing the original cost of the asset by its useful life. The resulting annual depreciation expense is added to accumulated depreciation each year. Fixed assets have different life expectancies and, thus, are depreciated at different rates. A portion of the original cost of equipment is moved from asset into expense each fiscal

Figure 6-1 Map 1

Certified 2002 diagnosis year

Certified based on one or more diagnosis years (1996–2001)

Figure 6-2   Map 2

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Certified 2002 diagnosis year

Certified based on one or more
diagnosis years (1996–2001)

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year. Eventually, all of the cost has been expensed and equipment asset value is zero. This financial accounting and analysis activity is called depreciation. The purpose of depreciation is to spread the cost of an asset over its useful life. The depreciation of long-term assets does not have a direct relationship to the activity of actually using the asset. It is not unusual to depreciate an asset over a five-year period but continue to use it for another five years.

STAFFING AND REGISTRY FUNCTIONS

Personnel cost is a major component of a central cancer registry budget. The types of staff needed for a registry are dependent on the various functions of the registry. These functions can be broadly grouped as follows: data collection, data processing, quality control, preparing reports and publications, conducting research, and other activities using the registry data.

Most administrators can develop some sort of creative financing plan to cover an operating budget for several years. As the registry matures, temporary cost savings alternatives can sometimes be developed without jeopardizing quality. For instance, some services can be sub-contracted outside the registry such as data entry, data processing, etc. However, this process can be expensive. Either additional funds must be appropriated or the scope of work will need to be reduced. However, this process can be expensive. Either additional funds must be appropriated or the scope of work will need to be reduced.

Data collection is the group of activities conducted to identify the cancer case, abstract data from the medical record or other documents, and code the abstracted data. The number of staff needed is dependent on the caseload of the registry, the geographic area of the registry, the method by which the data are collected, and the number of data items that are collected. Traditionally, the larger the geographic area in which the data collection is conducted, the more staff is needed. Advances in technology, web-based data collection.

Another factor that affects the number of staff in data collection is the source of the data. Cancer patients are increasingly being diagnosed and treated outside of hospitals. Thus, death certificates and pathology laboratory reports are increasingly being used to identify cases diagnosed and treated outside of the hospital. Increasingly, physicians' offices and other non-hospital diagnosing and treating facilities are queried and/or visited by cancer registry staff

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Table 6-1 Data Items for Automatic Updating   FC

Standard Item Name	Item Number
Name Last	2230
Name First	2240
Name Middle	2250
Name Maiden	2390
Social Security Number	2320
Sex	220

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to complete the information originally obtained from the death certificate and pathology laboratory reports.

STAFFING AND DATA QUALITY

In "Hurdles in Achieving Registry Certification, 1995-1997," the authors concluded that achievement of national standards for data quality was not related to registry size, age, extent of computerization, extensiveness of using computerized edits, or caseload per full-time equivalent (FTE) workload. However, indicators for the qualifications of staff may be a better measure of workload, and inefficiencies of operations may create perceptions of being short staffed, overworked, and a real inability to perform all necessary registry operations to produce high-quality data.

Job classifications used in the cancer registry are dependent on registry functions. For data collection and data quality functions, Certified Tumor Registrars (CTRs) are used. Information technology staff is used to develop and support information systems; database administrator, network systems engineer, programmer analyst, and systems analyst are some of the classifications used. Similarly, data analysis and other activities using registry data require job classifications such as biostatistician, research analyst, and epidemiologist.

One way of determining efficiencies of registry operations is to capture processing time of various registry operations. Current technology has provided a means of measuring productivity. The following are examples of reports generated from the California Cancer Registry.

These reports are examples of measuring productivity and can also be used to evaluate efficiencies of the data processing. When enhancements are made in the data management system, processing time should be less.

COST OF REGISTRY OPERATIONS

Organizations that provide funding for the registry are very interested in determining the cost of registry operations. The Centers of Disease Control and Prevention (CDC) recently published "The National Program of Cancer Registries: Explaining State Variations in Average Cost per Case Reported." The CDC intends to conduct in-depth analysis of individual state registries to estimate total cost

to report a cancer case. Similarly, the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program has a mechanism with the SEER registries to capture the cost of specific registry functions.

In coming years, there should be more data available on cost of the operations of central cancer registries in the United States. The role of the registry as a valuable resource in lessening the burden of cancer is enhanced when budgets and staffing are properly administered and efficiencies are achieved to support this valuable resource of cancer data.

STUDY QUESTIONS

1. Do the components of a budget normally follow an income and expense format?
2. Define *fixed costs.*
3. Define *variable costs.*
4. Define *overhead,* or *indirect costs.*
5. Identify three major categories of central registry expenses.

REFERENCES

1. Hotes JL, Howe HL, Wu XC, Correa CN. Hurdles in Achieving Registry Certification 1995-1997.: North American Association of Central Cancer Registries,; June 2002,: pages 1-9. Appendix A, B, C. cited 2005 September 22, 2005. Available from Internet URLat: http://www.naaccr.org/index.asp?Col_SectionKey=11&Col_ContentID=52
2. Weir HK, Berg GD, Mansley EC, Belloni KA. The National Program of Cancer Registries: eExplaining sState vVariations in aAverage cCost per cCase rReported. Prev Chronic Dis,. Jul 2005. Available fromat: URL: http://www.cdc.gov/pcd/issues/2005/jul/04_0124.htm.

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DEATH CLEARANCE

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INTRODUCTION

Death clearance is defined as "the process of matching registered deaths in a population against registered cancers in a population for two purposes: 1) identification of all deaths with cancer mentioned as a cause of death which are not found in the cancer registry, and 2) ascertainment of vital status for persons in the [cancer] registry."It is an essential procedure in the operation of a population-based registry to ensure complete reporting of incident cases. Standards and best-practice guidelines for some aspects of death clearance have been established, while others continue to be developed.

Death clearance in a population-based cancer registry is a two-step process. The first step is to link death records from the state's vital statistics office to registry records and to obtain death data for previously registered cancer cases. The second step is to identify those death certificates that mention cancer as one of the causes of death but that do not link to or match previously registered cases. Non-matched death certificates require further evaluation (commonly referred to as follow-back) to determine if they meet reportability requirements.

The registry must work closely with its state's vital statistics office and obtain access to computer files and paper death certificates. The registry needs to determine which data items and codes are used by the vital statistics office to categorize such items as cause of death, residency, and race or ethnicity, and which data items and codes may be released to the registry.

The registry also needs to become familiar with processing schedules and procedures of its state's vital statistics office in order to optimize scheduling of death clearance. The registry may need to negotiate a formal agreement with the vital statistics office covering access to death records, subsequent use of any information obtained, and costs.

In deciding when to perform death clearance, it is important to determine when all of the filed certificates have been incorporated into the database (including deaths of residents occurring out of state) and when the state's death certificate coding is complete. This is especially important if the registry receives periodic partial death files. The death certificates of residents of one state who die in another state are forwarded back to the state of residence via the Transcript Exchange Program, and it is important to the registry that these records be included in death clearance. All states' reporting of death certificates in the United States is submitted annually to the National Center for Health Statistics (NCHS), and is due to NCHS approximately 12 months after the end of the calendar year.

Caution should be taken when using the coded death certificate data prior to the NCHS submission, especially the coding of underlying cause of death. The vital records department may be performing follow-back query activities, and the results can alter the death record codes prior to the final submission. The data as submitted to the NCHS can be considered final, including the coded information for cause of death.

FIRST STEP

Sample Head 2

The first step, routine linkage of death records, is done to update the vital status of the matched cases already in the database. In population-based registries that conduct active patient follow-up, frequent death record linkage will prevent the generation of unnecessary follow-up inquiries.

Linkage of death records with registry files is a specific application of general records linkage, and many methods and algorithms have been used. Choice of a record linkage method depends on the data items available for linking, size of files to be linked, sensitivity and required, and system capabilities. The linkage will generally produce three outcomes: absolute or positive matches, possible matches. For example, if a match is made on all of the items in one of the two categories shown below, then it can be considered an "absolute" match:

1. National identification number (Social Security number), last name, first name, birth date, and sex

2. Soundex of last name, first name, birth date, and sex (Soundex is a phonetic encoding technique used to reduce the problems of sound-alike and misspelled names associated with record retrieval.)

If the match criteria are incompletely met, it can be considered a "possible" match. The possible matches are manually reviewed to determine if they are indeed matches. Review of case files, phone calls to providers, or correspondence with facilities may be required to verify possible matches.

Follow-up information is added to the database for those cases that are absolute matches and those determined by review to be matches. The data items in Table 11-1 may be automatically updated with information from the death record: The standard item names and numbers in Tables 11-1 and 11-2 are those of the North American Association of Central Cancer Registries.

For the items in Table 11-2, the death record information should be compared with the registry files and consolidated or updated where possible. For example, unknown values may be replaced by known values from the death record, or the death record may have more accurate information than the registry record.

For matched deaths with cancer as a cause of death, it is also important to identify discrepancies between the cancer cause-of-death codes and the diagnosis codes in the registry database. For example, the death certificate may mention one type of cancer and the registry database another type. A review of both the death certificate and the registry abstract file may be necessary. This review could identify possible additional primary sites that would require follow-back to obtain more information. The end result may be the addition of another primary site to the registry's database.

A review is also recommended when the registry's database has an unknown primary site and the death certificate mentions a specific primary site. Follow-back may reveal that the primary site on the death certificate is indeed a metastatic site and the primary was never identified. Alternately, the more specific primary site mentioned on the death certificate may have been determined to be the primary. The registry database should be updated based on the review. Editing and review of histologically unconfirmed cases can also be performed at the time of death clearance. If the cancer is not mentioned on the death certificate, the diagnosis of cancer may have been ruled out after the case was ascertained and prior to death, or at the time of autopsy. The review of these cases may result either in the removal of an unconfirmed case from the registry database or in the case being retained in the registry database.

SECOND STEP

The second step of death clearance in a population-based cancer registry is the identification of death records that mention cancer as one of the causes of death but do not link with previously registered cases. These cases require follow-back to determine their reportability. The follow-back process attempts to ensure that every cancer death in the file used for calculating cancer mortality statistics is accounted for in the file used for incidence reporting. Not all mortality records will appear in the incidence file. A determination will have been made. These cases require follow-back to determine their reportability. A determination will have been made.

Table 11-1 Data Items for Comparison and Possible Updating

Standard Item Name		Comment
Date of Last Contact	1750	Date of death from the death certificate
Vital Status	1760	
Follow-Up Source Central	1791	Code indicating that the information came from the death certificate
Cause of Death	1910	Code for underlying cause of death from death certificate
ICD Revision Number	1920	Version of the International Classification of Diseases used to code the cause of death
Place of Death	194	

Although this chapter speaks of cancer as a cause of death, it should be noted that from 2004 forward, benign tumors of the brain and other parts of the central nervous system are also included in the cancer registry, as required by federal law and other standard-setter requirements. Death certificates with these tumors mentioned as causes of death should be handled like death certificates.

For an unmatched cancer death that occurs in a facility that reports to the registry (e.g., a hospital), the presumption is that the case was missed in routine reporting, and a request is made for an abstract to be completed. The reporting facility's abstractor then either submits an abstract or verifies that an abstract is not required because, for example, the cancer was originally diagnosed prior to the registry's reference date, the case has already been submitted. For cancer deaths that did not occur in reporting hospitals, follow-back must be made to the certifying physician, nursing care facility, hospice, or coroner, requesting an abstract or at least minimal history information. Date and place of diagnosis and the patient's residency at diagnosis are the most important items to request, as well as any history of prior hospitalizations for the cancer.

Sample Head 3

A follow-back query on a death that did not occur in a hospital may reveal that the patient had previously been hospitalized for cancer. In this event, an abstract should be obtained from the hospital.

All information received from a follow-back query is reviewed to determine if the case meets reportability requirements for inclusion. Depending on those findings, the case can be either incorporated into the registry database or deleted.

Timing can cause complications in death certificate follow-back. An overlap in procedural activities could occur, and the abstracted case may be in transit and not processed by the central registry at the time of linkage between the death data and the registry database if a hospital's abstracting is delinquent. Death clearance may identify cases that are late but would eventually be reported, causing extra follow-back work. On the other hand, if there is substantial delay in death clearance (e.g., clearing deaths from 2006 in 2008), follow-back is hampered because some physicians will have moved or retired, records will have been stored off-site or destroyed (especially with nursing homes), and providers will not remember the patients.

The following are examples of cases that could be excluded or deleted because they do not meet reportability requirements:

- The cancer was diagnosed prior to the reference date of the registry.
- Later autopsy results ruled out the diagnosis of cancer.
- The death certificate incorrectly mentioned cancer.
- The case is a non-reportable diagnosis (e.g., basal or squamous cell carcinoma of the skin).
- The person was a non-resident of the coverage area at the time of diagnosis. (However, many registries do not exclude non-residents since they share cases with other states where their patients may have resided at diagnosis.)

After all follow-back sources have been exhausted and no other information on the case is available, the case is entered or retained on the registry's database as a death-certificate-only (DCO) case. This designation is carried in the field Type of Reporting Source (standard item number 500). This designation indicates that the only source of information is a death certificate that mentions cancer.

DCO cases are likely to be clinically diagnosed cancers in patients who were not hospitalized or whose cancers were not treated. Cancer cases diagnosed outside the registry's catchment area may also be DCO cases. It is possible that later information will become available and the DCO designation may be changed.

Sample Head 4 There are standard conventions used in abstracting DCO cases. For example, the date of death is always used for the date of diagnosis of the cancer, stage of disease at diagnosis is always coded unknown, the cases are classified as not histologically confirmed, and they are always coded as untreated. These conventions may be modified over time as standard-setting agencies revisit procedures.

It is important to track the progress of death clearance, both to confirm that all follow-back is completed and to provide information regarding results. One method of tracking is to immediately assign a unique identification number to the case and accession it onto the registry's database with a DCO Type of Reporting Source code. The record will then be updated as follow-back is accomplished. Another method is not to accession the case, but to assign it a unique control number.

ANALYSIS OF DEATH CLEARANCE RESULTS AND THEIR USE IN MONITORING COMPLETENESS OF REPORTING

The results of death clearance can provide useful information to the registry on the adequacy of routine reporting. By keeping detailed records of follow-back results, by facility and source within the facility, the registry can identify deficiencies in their routine casefinding, such as the following:

- Hospitals with more than an occasional missed case, (especially if the cases could have been identified from the same source within the hospital) indicating a need for review of the hospital's casefinding procedures
- Nursing homes, hospices, or individual physicians accounting for more than an occasional missed case
- Out-of-state facilities where the registry's cases are being seen

The North American Association of Central Cancer Registries' requirements for certification include parameters for the allowable number of DCO cases. To be certified at the gold level, the percentage of cancers diagnosed only by a death certificate should not exceed 3% of all cancers registered in a given year after follow-back.

CONCLUSIONS

In summary, death clearance in a population-based cancer registry should be performed on a routine basis. It should include the linkage of death certificate information with previously registered cases and the follow-back of death certificate cases that mention cancer but are not in the registry. Quality control assessments of the completeness of reporting and case ascertainment can be interpreted across registries only if this process has been standardized. Use of comparable methodology and procedures that follow recommended standards will permit comparisons of data among registries. Death-certificate-only cases should be monitored and used as a measure of completeness of reporting in a population-based cancer registry.

STUDY QUESTIONS (TRUE OR FALSE)

1. In recent years, new techniques have been developed so death clearance is no longer necessary for accurate survival calculations.
2. Death-certificate-only cases are not reportable because they are not pathologically confirmed.
3. For registries that do not calculate survival, there is no need for death clearance.
4. Death certificate follow-back refers to a method of rigorous abstracting.
5. Death clearance is a measure of a registry's quality. In general, the more new cases found by death clearance, the better.

REFERENCES

1. Seiffert JE, Young JL, Granoien WL. Death Clearance: Procedures for Central Registries. Sacramento, Calif: North American Association of Central Cancer Registries; September 1, 1998.
2. Havener L, ed. Standards for Cancer Registries Volume III: Standards for Completeness, Quality, Analysis, and Management of Data. Springfield, Ill: North American Association of Central Cancer Registries; October 2004.
3. NAACCR Death Clearance Best Practices Workgroup, eds. Series V: Resolving Death Clearance Issues, 2002. Procedure Guidelines for Cancer Registries. Springfield, Ill: North American Association of Central Cancer Registries; January 2003.
4. Seiffert JE, Hoyler SS, McKeen K, Potts M. Casefinding, Abstracting, and Death Clearance. In Menck H, Smart C. Central Cancer Registries: Design, Management, and Use. Chur, Switzerland: Harwood Academic Publishers; 1994.
5. Havener L, Hultstrom D, eds. Standards for Cancer Registries Volume II: Data Standards and Data Dictionary, 11th ed., ver. 11.1. Springfield, Ill: North American Association of Central Cancer Registries; April 2006.