

**SERIES III  
PREPARING A POLICY  
AND PROCEDURE  
MANUAL**



**Edited by:  
Registry Operations Committee  
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## Introduction

The primary purpose of any cancer registry is to collect complete, timely, and high-quality data that are available for use for cancer control and research. The multiple aspects of data collection that are specific to the population-based cancer registry require the program staff to evaluate all operational and procedural activities and then identify those activities that have the greatest impact on the timeliness, quality, and completeness of data collection.

Because experience and staffing vary considerably, the Registry Operations Committee of the North American Association of Central Cancer Registries (NAACCR) adopted as its charge the development of procedure guidelines for various operational activities performed by population-based cancer registries. *This guideline focuses on preparation of a central cancer registry policy and procedure manual.*

Policy and procedure manuals are used by organizations to document why and how something is done. Cancer registries, like other organizations, need a document that describes specific policies and work procedures. Section II.A.3.a of NAACCR's Standards for Completeness, Quality, Analysis, and Management of Data (Standards for Cancer Registries, Volume III) states:

Permanent, current, widely distributed written documentation of all aspects of the registry's definitions and methods is essential to establish standardization, maintain continuity of meaning, document changes over time, develop training, and inform data users. The documentation is usually in the form of procedure manuals, coding manuals, and other manuals.

The development of a policy and procedure manual is time intensive. The intent of this document is to provide information on the various topics that might be included in the manual of a population-based cancer registry. Based on experience and the number of years in operation, not all activities will be performed by all registries. The document is a comprehensive list of cancer registration topics.

1. The document is divided into sections that describe information pertaining to each particular topic.
2. All topics included in this document do not apply to every registry and do not have to be included in every registry's policy and procedure manual.
3. This list should be used as a guide for documentation of registry policies and procedures.
4. Potential topics are listed with a description of necessary documentation.
5. The topics included have been assigned a priority rating: high (H), medium (M), or low (L). The rating identifies those topics that should be addressed immediately and those that can be addressed at a later date.
6. Additional reference materials and resource documents are listed at the end of each section.

It is recommended that all registry policies and procedures be stored in an electronic file that is accessible to all registry staff through a desktop computer. Some central registries have a departmental Intranet that may be used for storage of policy and procedure documents. If the topics listed in this document exist as different registry documents, the Registry Operations Committee recommends that those documents also be stored electronically with the policies and procedures. It is not necessary to rewrite these documents, but storage with the policies and procedures allows staff ready access to documents necessary for job completion.

## Section 1: Policy and Procedure Maintenance

### Priority

#### **H 1. Format**

*Describe how your manual will be maintained, such as in hardcopy (paper) or electronically. If hardcopy is maintained, describe where the master copy will be located. If stored electronically, describe the location of the files. Describe the standard format for policies and procedures.*

A. Paper copy of procedure manual.

B. Electronic copy of procedure manual available on a shared drive or on an internal Web site.

#### **L 2. Staff position responsible for coordinating and reviewing all policy and procedure updates**

*Describe who will be responsible for maintaining the schedule of review to ensure that procedures are reviewed and updated on the agreed schedule.*

#### **L 3. Staff position responsible for writing and updating each section of policies and procedures**

*Describe who is responsible for writing each of the policies and procedures. Example: The quality control coordinator will be responsible for maintaining all policies and procedures in the quality control section; the secretary will be responsible for maintaining all administrative policies and procedures.*

#### **M 4. Staff position responsible for approving and signing all policies and procedures**

*Describe who is responsible for reviewing, approving, and signing off on all updates and new policies and procedures.*

#### **L 5. Schedule for review and update of policies and procedures**

*Describe the schedule for review of all policies and procedures. Example: All policies and procedures will be reviewed and updated as necessary, but not less than annually. New policies and procedures will be written as needed.*

#### **L 6. Documentation of changes**

*Describe how changes will be documented. Example: On all policies and procedures, record the original date of implementation and author and the revision date and author.*

#### **M 7. Method of distribution**

*Describe how the policies and procedures will be distributed. Example: All new employees will be told where the electronic files are stored and where the paper copy is stored.*

#### **L 8. Assurance of use**

*Describe how you will ensure that current staff are utilizing approved procedures and that all new employees have reviewed policies and procedures that apply to their jobs.*

See NAACCR Standards for Cancer Registries, Volume III, Section II.A.3: Procedure Manuals, Coding Manuals, and Other Documentation.

**Reference**

NAACCR. Standards for Cancer Registries, Volume III. Standards for Completeness, Quality, Analysis, and Management of Data. Springfield, IL: North American Association of Central Cancer Registries, September 2000.

## Section 2: General Registry Information

### Priority

#### **H 1. Cancer registry mission statement**

*Describe the history and purpose of the registry.*

#### **H 2. Contacts**

*Describe key contacts within the registry. Information may include:*

- A. Registry name, address, telephone and fax numbers, and e-mail address.
- B. Director's name, title, and credentials.
- C. Primary contact's name, title, and credentials.
- D. Information systems contact's name.
- E. Quality control contact's name.
- F. Data analysis contact's name.
- G. Statistical contact's name.

#### **H 3. Registry information**

*Describe key information regarding the registry, which may include:*

- A. Type of registry.  
*Example: The Central Cancer Registry (CCR) is a population-based registry for the State of Somewhere.*
- B. Institutional affiliation  
*Example: The CCR is a program of the State Department of Health.*
- C. Organizational chart.
- D. Geographic areas covered by the registry.
- E. Population size of the geographic area.
- F. Reference date: diagnosis year data collection began.
- G. Approximate number of records processed annually.
- H. Number of annual unduplicated incident cases.
- I. Number of annual unduplicated *in situ* cases.
- J. Estimated completeness percentage and the methods used to make the estimate.
- K. Funding sources and the percentages from each source.  
*Example: Fifty-nine percent of the funding for the CCR is provided by the state budget and forty-one percent is funded through the National Program of Cancer Registries.*

#### **M 4. Administration**

- A. Staff and line relationship.

*Provide a broad description of the departmental structure and supervisory responsibility. Example: The CCR is in the Epidemiology Section of the State Health Department, and the CCR director reports to the director of the Epidemiology Section. The CCR has four branches: data analysis, data management, program operations, and quality management and field operations. Managers of these branches report to the director of the CCR.*

- B. Performance measures.

*Describe any performance measures the registry is required to track, such as the number of cluster investigations and the number of responses to inquiries.*

**Priority**

- C. Confidentiality.
    - 1. Legal definition as provided in state statutes.
    - 2. Confidentiality policy.
    - 3. Employee confidentiality agreement.
    - 4. Procedures for release of cancer registry data.
    - 5. Standard report requirements.  
*Describe any standing departmental reports, their schedules, and the staff position responsible for generating the reports. Reports might include monthly state administrative reports and/or federal or provincial (e.g., SEER, NPCR) reports.*
  - D. Training
    - 1. Registry software.  
*Describe training procedures for use of software.*
    - 2. Continuing education.  
*Describe how the registry will address training needs for staff, including new employees, and maintain annual training needs.*
  - E. Travel requirements  
*Describe departmental procedures for travel.*  
*Example: Many CCR staff travel as part of their jobs. All travel documentation and related correspondence must be processed by the CCR secretary and forwarded to the CCR director for initials.*
  - F. Specific responsibilities.  
*Describe any specific duties such as participation in special studies.*
- H 5. Reporting sources**  
*List all reporting sources and the approximate percentage of cases from each source. This may be the location of an electronic file.*
- H 6. Reporting source facility information**  
*Describe how information on reporting facilities is maintained. This may be in a hardcopy file or a database maintained in a shared computer file.*
- A. List of reporting facilities.  
*Describe the information recorded for each reporting facility, which might include:*
    - 1. Reporting facility name and address.
    - 2. Primary contact's name, telephone and fax numbers, and e-mail address.
    - 3. Facility administrator/CEO.
    - 4. Department responsible for case reporting.
    - 5. Directions to facility.
    - 6. Reporting schedule.
    - 7. Annual expected number of cases.
    - 8. Reporting format.
    - 9. Reporting software.
  - B. Document the staff position responsible for maintaining the reporting facility file.
- L 7. Signature authority**  
*Describe signatures required on registry correspondence and reports. List signatures required for activities such as instate travel, routine purchases, and computer equipment purchases.*  
*Example: Signature authority resides with the CCR director. For certain documents or occasions, this may be shifted to another position.*

**Priority****L 8. Budget oversight**

*Describe who is responsible for the registry budget. Document any standing meetings for the purpose of planning and coordinating budgetary issues.*

*Example: The CCR budget officer provides the principle coordination of all registry budget matters. This post with the registry director has the direct responsibility for fiscal operations of the registry. The budget officer and the registry director will meet monthly to review the current status of the budget.*

**H 9. Legislation**

*Include copies of all legislation relating to the registry, which may include:*

- A. Legislation and/or regulations authorizing the registry and regulating data submission.
- B. Legislation and/or regulations defining penalties for noncompliance.
- C. Confidentiality regulations.

See NAACCR Standards for Cancer Registries, Volume III, Section I.A.1: Legislation and Regulations.

**L 10. Registry data collection and coding manuals**

*Describe the manuals used by the registry by year of use.*

*Example: From 1991 through 2000, site and histology were coded using ICD-O-2; beginning in 2001, ICD-O-3 was used to code site and histology.*

See NAACCR Standards for Cancer Registries, Volume III, Section I.A.2: Reportability Definitions; and Section II.A.3: Procedure Manuals, Coding Manuals, and Other Documentation.

**H 11. Advisory boards**

*Describe all advisory boards assisting the registry. These may include:*

- A. Community advisory boards.
- B. Medical advisory boards.
- C. Medical consultants/advisors.

**H 12. External liaisons**

*Describe all agencies that assist the registry and the nature of the relationship. These may include:*

- A. Universities.
- B. Schools of Public Health.
- C. American Cancer Society.

See NAACCR Standards for Cancer Registries, Volume III, Section I.B.4: Liaison With Outside Agencies and the Medical Community.

**L 13. Personnel**

*Provide documentation of personnel, which may include:*

- A. Job descriptions and duties for all staff.  
*If the job descriptions are not part of the policy and procedure manual, state all places this information can be found.*
- B. Registry organization chart.
- C. Procedures for filling job vacancies.

**Priority**

- D. Career development, including continuing education, training courses, and seminars.  
*Provide a statement of departmental support for general career development and any limitations related to specific positions. Describe procedures for request for training and the approval process.*
- E. Performance evaluations.  
*Describe how staff will be evaluated. Include how often evaluations will be performed and which staff is responsible for performing evaluations.*  
*Example: The CCR used a performance management review system to evaluate staff performance and development. Forms providing a synopsis of work plans are prepared at the beginning of each fiscal year.*

See NAACCR Standards for Cancer Registries, Volume III, Section I.A.3: Staffing Guidelines for Data Collection; Section II.A.2: Staffing Guidelines for Data Quality; Section III.A.3: Staffing Guidelines for Data Analysis and Reporting; and Section IV.A.4: Staffing Guidelines for Data Management.

**L 14. Registry resources**

*Describe procedures for:*

- A. Scheduling conference rooms
- B. Use of audiovisual equipment.

**Reference**

NAACCR. Standards for Cancer Registries, Volume III. Standards for Completeness, Quality, Analysis, and Management of Data. Springfield, IL: North American Association of Central Cancer Registries, September 2000.

## Section 3: Office Management

### **Priority**

#### **L 1. File management**

*Describe procedures for maintenance of registry files including personnel files and procedures for document storage. List the staff position responsible for the activities.*

#### **L 2. Correspondence**

*Describe the procedures for telephone inquiry triage. These may include:*

- A. List of staff responsible by subject.
  1. Staff position responsible for all media calls.
  2. Staff position responsible for answering public inquiries.
  3. Staff position responsible for answering reporting facility questions.
- B. A description of procedures for answering incoming phone calls.
- C. A description of incoming mail processing procedures.
- D. A description of procedures for outgoing correspondence.
- E. Documentation of the staff position responsible for maintenance of mailing lists.

#### **L 3. Time and attendance**

*Describe procedures related to time cards or attendance sheets, sick leave, and vacation scheduling.*

#### **L 4. Travel**

*Describe travel procedures, which may include:*

- A. How to obtain travel approval.
- B. Travel guidelines.
- C. How to complete reimbursement forms.

#### **L 5. Standard administrative reports**

*These may include:*

- A. Monthly departmental reports.
- B. Reports to NPCR, SEER, Statistics Canada.

See NAACCR Standards for Cancer Registries, Volume III, Section II.B.3: Reports.

#### **L 6. Grant responsibility**

*List current grants and staff position responsible for monitoring them.*

#### **L 7. Purchasing supplies and equipment**

- A. Staff position responsible for purchasing supplies.
- B. Procedures for purchasing supplies.

**Priority****L 8. Publications**

*Describe procedures and staff positions responsible for maintaining registry publications, which may include newsletters, standard reports, brochures, and annual report.*

See NAACCR Standards for Cancer Registries, Volume III, Section II.B.3: Reports.

**Reference**

NAACCR. Standards for Cancer Registries, Volume III. Standards for Completeness, Quality, Analysis, and Management of Data. Springfield, IL: North American Association of Central Cancer Registries, September 2000.

## Section 4: Hardware and Software: Registry Operating System and Data Management

### Priority

#### **H 1. Hardware**

*Describe the hardware used by the registry. This may include:*

- A. Computer hardware and operating system software.
  1. Ownership.  
*Example: The CCR is part of the Health Department LAN.*
  2. Configuration: model, RAM, CPU speed.
  3. Operating system.  
*Example: Windows95*
  4. Laptop computers.
- B. Internet access.  
*Example: The CCR Internet service is provided through the Department of Health and is accessible through the LAN system operated by the Health Department.  
List the file location and any restrictions.*
- C. Data storage media.
- D. Type of optical imaging system.
- E. Number of users on network.
- F. Other peripherals such as printers.

See NAACCR Standards for Cancer Registries, Volume III, Section V.A.2: Hardware Requirements.

#### **H 2. Software**

*Describe all computer software programs used by the registry.*

- A. Data management program.
  1. Whether it is commercial or custom designed and developed.
  2. Primary components of the data management software.
  3. Database design: hierarchal versus relational.
  4. Parameter maintenance: how variables are updated.
  5. Internal database matching capabilities.
  6. External database matching capabilities.  
*Example: Matching to vital statistics death database for death clearance.*
  7. Storage of source documents.
  8. Geocoding capabilities and whether geocoding is provided in-house or by a commercial vendor.
  9. Utility programs.

See NAACCR Standards for Cancer Registries, Volume III, Section IV.A: Data Management: Structural Requirements.

**Priority**

- B. Data analysis software.
  - 1. Statistical analysis software.  
*Example: SAS, SPSS, Systat, BMDP, Lotus 123, Microsoft Excel, QuattroPro, HIRS, EpiInfo, Microsoft Access, SEER\*Stat, SEER\*Prep.*
  - 2. GIS programs.
- C. Management report program.
- D. Record linkage programs.  
*Describe both internal and external programs such as Automatch, MatchWare, GRLS, custom design, and Linkpro. Indicate whether the program uses probabilistic or deterministic matching routines.*
- E. Data edits.  
*Describe whether the edits are in-house, commercial vendor, or the NAACCR metafile. Describe procedures for adding, deleting, and changing edits as well as how to generate a list of the edits used.*
- F. Office management.  
*Describe the software programs used for word processing, graphics, and spreadsheets.*

See NAACCR Standards for Cancer Registries, Volume III, Section IV.A.3: Software Requirements.

- H 3. Data security**  
*Describe Internet firewalls, user passwords, security levels, physical security system, data encryption, backup, and recovery.*

See NAACCR Standards for Cancer Registries, Volume III, Section I.B.8.b)(1): Standards for Policies and Procedures for Data Security.

- H 4. Data items**  
*List all data items collected and their definitions. Indicate whether they are standard NAACCR data items, state/province-specific items, or custom and nonstandard items.*

**Reference**

NAACCR. Standards for Cancer Registries, Volume III. Standards for Completeness, Quality, Analysis, and Management of Data. Springfield, IL: North American Association of Central Cancer Registries, September 2000.

## Section 5: Data Processing Operations

### Priority

#### **H 1. Reporting requirements**

*Describe the required format. Include a definition of reportable cases, a reportable list, the required data set, required dates for case submission, standards, multiple primary rules, and ambiguous terminology. If this information is described in a separate document, state where the information is located.*

See NAACCR Standards for Cancer Registries, Volume III, Section I.A.1.c)(1): Standards for Reporting Requirements; and Section I.A.2: Reportability Definitions.

#### **H 2. Case ascertainment**

A. List of the number of reporting facilities by facility type.

1. Hospitals.
  - a. With American College of Surgery Certificate of Competency (ACOS-COC) approved cancer program.
  - b. Without ACOS-COC approved cancer program.
2. Ambulatory surgical treatment centers.
3. Freestanding radiation treatment centers.
4. Private pathology laboratories.
5. Physicians.
6. Other facilities.

See NAACCR Standards for Cancer Registries, Volume III, Section I.B: Access to Source Data and Completeness of Reporting: Process Standards.

B. Procedures for monitoring changes in case reporting from facilities.

*Describe procedures used. These may include management reports that list the number of cases received by the facility by month or the number of cases received by month of diagnosis by the facility.*

C. Methods used to establish expected numbers.

1. Method used to calculate the expected number of cases for a report year.
2. Method used to calculate the expected number of cases for each reporting facility.

See NAACCR Standards for Cancer Registries, Volume III, Section I.B.11: Monitoring Completeness of Reporting and Ensuring Compliance by all Facilities and Practitioners.

D. Methods used to monitor case completeness.

*Describe methods used, which may include:*

1. Observed versus expected: investigation of deviations between the number of expected cases and observed cases.
2. Pattern analysis.
  - a. Incidence rates and frequencies higher than mortality.
  - b. Age distribution.
  - c. Percentage of microscopically confirmed cases.
  - d. Incidence-to-mortality ratio.

**Priority**

- e. Percentage of death certificate only cases.
- f. Percentage of cases reported only by a pathology laboratory.

See NAACCR Standards for Cancer Registries, Volume III, Section I.C.2: Observed Versus Expected Case Counts.

- E. Method of calculation of case completeness rate.  
*Describe methods used, which may include:*
  - 1. ACS Cancer Facts and Figures comparison.
  - 2. NAACCR standard.
- F. Casefinding completeness audits.  
*Describe procedures used to complete casefinding audits. These may include:*
  - 1. Sampling strategy for facility selection.
  - 2. Frequency of audits.
    - a. Percentage of facilities audited on an annual basis.
    - b. Method used to ensure that all facilities are audited within a designated timeframe.
  - 3. Methods used.
    - a. Time period audited.
    - b. Method dependent on size of institution and/or caseload.
  - 4. Sources reviewed in performing casefinding audits.
  - 5. Analysis plan.
  - 6. Followback.

See NAACCR Standards for Cancer Registries, Volume III, Section I.B.12: Casefinding Audits.

- G. Monitoring timeliness.  
*Describe the procedures used, which may include:*
  - 1. SEER, NAACCR, Statistics Canada, and NPCR timeliness standards.
  - 2. Percentage of cases reported to registry within 6 months from the date of diagnosis.
  - 3. Followback to facilities.

See NAACCR Standards for Cancer Registries, Volume III, Section I.C.4: Timeliness of Central Registry Reporting.

**H 3. Field program: abstracting**

- A. Administration.  
*Describe the process of case abstracting performed by the registry. Processes may include:*
  - 1. Staff and line relationships between persons responsible for abstracting.
    - a. Commercial contract staff.
    - b. Registry staff.
  - 2. Performance measures for staff performing case abstracting.
  - 3. Confidentiality procedures for abstracting staff.
  - 4. Standard report requirements.
- B. Training.  
*Describe training program for registry abstractors.*
  - 1. Training program for the use of registry abstracting software.
  - 2. Continuing education policies for abstracting staff.

**Priority**

See NAACCR Standards for Cancer Registries, Volume III, Section I.A.3.b)(2): Standards for Continuing Education; Section I.B.10: Training in Casefinding and Multiple Primary Determination; and Section II.B.2: Training for Improved Data Quality.

- C. Travel requirements.  
*Describe travel requirements for field staff performing case abstracting.*
- D. Specific responsibilities.  
*Describe other activities expected of abstracting field staff such as participation in special studies and record-keeping requirements.*
- E. Facility selection criteria.  
*Describe how facilities are selected for case abstracting.*  
*Example: All facilities with fewer than 100 beds.*
- F. Facility schedules.  
*Describe how often facilities are visited for case abstracting.*

See NAACCR Standards for Cancer Registries, Volume III, Section I.A.3: Staffing Guidelines for Data Collection.

**H 4. Training program**

*Describe training programs and continuing education provided by the registry to staff from reporting facilities. These may include:*

- A. Regional meetings open to all facility reporters.
- B. Presentations at local Cancer Registrar Association meetings.
- C. Individual training based on assessment of needs determined by audit findings or by a review of submitted cases.

**M 5. Data acquisition manuals**

*Describe the maintenance responsibility and methods of distribution of data acquisition manuals.*

**H 6. Data entry**

*Describe procedures and schedules for transmitting data to the registry. These may include:*

- A. Documentation of receipt of data.
- B. Notification of receipt of data to reporting facility.
- C. Instructions for data entry of paper abstracts.
- D. Instructions for downloading electronic data to database.
- E. File review and preparation such as suspense files.
- F. Acceptance criteria.
- G. Data flowchart.
- H. Source document storage media.
  - 1. Registry database file.
  - 2. Microfilm.
  - 3. Optical image.

**H 7. Internal matching and linkage**

- A. Method for case matching.  
*Describe matching method used and whether it is manual or computerized.*
- B. Match criteria.  
*Describe the data items used as patient matching criteria.*

**Priority**

- C. Categories of matching.  
*Example: Absolute match, potential match, possible match.*

**H 8. Consolidation**

- A. Methods.  
*Describe the methods used to consolidate data.*
- B. Data items.  
*Define which data items are consolidated.*

See NAACCR Standards for Cancer Registries, Volume III, Section IV.B.6: Record Consolidation.

**L 9. Processing management reports**

- Describe reports used to monitor internal registry processes. These may include:*
- A. Bucket report: status report of cases in process by year of diagnosis and by occurrence in each process step.
  - B. Aging report: report of amount of time required to process cases.

See NAACCR Standards for Cancer Registries, Volume III, Section IV.B.3.b)(1): Standards for Management Reports.

**References**

NAACCR. Standards for Cancer Registries, Volume III. Standards for Completeness, Quality, Analysis, and Management of Data. Springfield, IL: North American Association of Central Cancer Registries, September 2000.

NAACCR. Instructional Module for Cancer Registries. Cancer Registry Management Reports: Design and Implementation. Springfield, IL: North American Association of Central Cancer Registries, June 1998.

**Other Resources**

NAACCR. Instructional Module for Cancer Registries. Multiple Lesions and Cancer Registry Case Definitions. Springfield, IL: North American Association of Central Cancer Registries, August 1997 (revised July 2000).

NAACCR. Instructional Module for Cancer Registries. Timeliness of Cancer Reporting, Assessment and Improvement. Springfield, IL: North American Association of Central Cancer Registries, April 1998.

Report of the Record Consolidation Committee to NAACCR. Central Cancer Registry Record Consolidation: Principles and Processes. Springfield, IL: North American association of Central Cancer Registries, September 1999.

## Section 6: Death Clearance

### Priority

#### **M 1. Timing for linkage**

*Describe the criteria for linkage to death tapes. These may include:*

- A. Completeness of registry files.
- B. Completeness of facility reporting.
- C. Completeness of out-of-state reporting.
- D. Completeness of reporting from military and other federal facilities.
- E. Inclusion of cases identified through casefinding audits.
- F. Completeness of death files.

#### **H 2. Frequency of linkage**

*Describe the schedule for linkage to the death tapes, such as the use of quarterly tapes, and a year-end tape that includes cases not included on quarterly tapes.*

- A. Linkage by year of diagnosis.
- B. Relinkage for previous years.

#### **H 3. Method to access computer files and death certificates from the Vital Statistics Department**

- A. Tapes.
- B. Microfiche or microfilm.
- C. Paper documents.

#### **H 4. Determination of vital statistics codes**

*Describe which death certificate fields are coded and can be matched electronically to registry files. These may include:*

- A. Cause of death: underlying and multiple causes.
- B. Place of death.
- C. Demographics.

#### **H 5. Formal agreement with the Vital Statistics Department covering access to death certificates**

*Copy of formal written agreement documenting all interactions, which may include:*

- A. Access to electronic files.
- B. Access to hardcopies of death certificates.
- C. Confidentiality.
- D. Payment.

#### **M 6. Level of automation**

- A. Consolidation.

*Describe the level of automatic consolidation that can be done for exact matches and partial matches.*

- B. Updating information.

*Describe which information can be automatically updated from the death certificate file and which information will have to be updated manually.*

**Priority****H 7. Linkage criteria**

*Describe which death certificates are used to match with the registry. Are all cases in the registry matched against the death tape regardless of cause of death, or are only those with cancer as a cause of death included?*

**M 8. Criteria to determine match, no match, and possible match cases**

*Describe the criteria used to determine matching and nonmatching cases. These may include:*

- A. Automatic matching all data items for the cases that are an absolute match.
- B. Review when known value differs from the death certificate value.
- C. Review of death certificate and abstract file when cause of death primary site is different from the primary site in the registry file.

**H 9. Replacement of unknown values**

*Describe when unknown values for data items in the database are replaced with values from the death certificate. Data items may include date of death, race, occupation/industry, birthplace, social security number, and marital status.*

**H 10. Resolution of conflicting information**

- A. Multiple primaries.

*Describe procedures used to determine whether a patient has multiple primaries when the primary site on the registry and the primary site on the death certificate differ.*

- B. Demographic information.

*Describe procedures for resolution when there are differences in demographic information on the registry and the death certificate. These may include data items such as sex, race, and birthplace.*

**H 11. Replacement of unknown primary site on the registry when the death certificate records a specific primary site**

*Describe when or if an unknown primary site on the registry is replaced with a known primary site from the death certificate.*

**H 12. Review of unmatched death certificates**

- A. Followback.

*Describe information used to determine which death certificates to follow back.*

- B. Followback sources.

*Describe the sources used when performing followback.*

**H 13. Method of followback for unmatched death certificates**

- A. Followback timelines.

1. Timing of first request.
2. Time intervals for subsequent contacts.

- B. Followback forms.

*Describe the forms used for followback. These may include facility followback forms, physician followback forms, coroner followback forms, and nursing care facility followback forms.*

- C. Subsequent followback methods.

*Describe subsequent followback methods used, which may include second letters or phone calls.*

**Priority**

D. Followback tracking methods.

*Describe methods used to track the followback performed.*

E. Materials sent with followback letters.

*Describe any materials sent with followback letters. These may include copies of death certificates or a copy of the registry reporting law.*

**H 14. Resident death certificate information from other states**

*Describe the method for obtaining death certificate information for cases that expired outside of the registry state. This may include matching with the National Death Index.*

**H 15. Abstracting death certificate only (DCO) cases**

*Describe:*

A. When DCO cases are abstracted.

B. Who on staff abstracts the cases.

C. Abstracting instructions for DCO cases.

1. Date of diagnosis.

2. Stage.

3. Diagnostic confirmation.

4. Treatment.

**H 16. Sharing death certificate information**

*Describe if and how death certificate information is shared with other entities. This may include sharing information with other states and sharing information with hospital cancer registries.*

**H 17. Calculation of the DCO rate**

*Describe the method used to calculate the registry DCO rate.*

See NAACCR Procedure Guidelines for Cancer Registries, Series II: Calculating the Death Certificate Only (DCO) Rate.

**H 18. Acceptable percentage of total caseload DCO cases**

*Describe the method for monitoring DCO cases and the standard used to determine the acceptable threshold such as the NAACCR certification standard.*

See NAACCR Standards for Cancer Registries, Volume III, Section I.C.1: Percent Death Certificate Only.

**L 19. Monitoring DCO rates**

A. Identification of problem facilities.

B. Comparisons to standards such as NAACCR and SEER.

**M 20. Coding the underlying cause of death**

*Document the coding system, such as ICD-9 or ICD-10, used each year to code underlying cause of death.*

See NAACCR Standards for Cancer Registries, Volume III, Section I.B.9: Death Clearance.

### **References**

NAACCR. Standards for Cancer Registries, Volume III. Standards for Completeness, Quality, Analysis, and Management of Data. Springfield, IL: North American Association of Central Cancer Registries, September 2000.

NAACCR. Instructional Module for Cancer Registries. Death Clearance. Springfield, IL: North American Association of Central Cancer Registries, September 1998.

### **Other Resources**

NAACCR. Procedure Guidelines for Cancer Registries, Series II: Calculating the Death Certificate Only (DCO) Rate. Springfield, IL: North American Association of Central Cancer Registries, June 2000 (original release).

## Section 7: Case-Sharing Agreements

### Priority

#### **M 1. Process for establishing case-sharing agreements**

*Describe:*

- A. Procedure for determining which states will be targeted for case sharing.
  1. Evaluation of migration patterns for cancer patients in your state, including the use of major cancer centers in bordering states or treatment for cancer specialties such as pediatrics.
  2. Evaluation of cancer incidence rates to identify the impact case sharing may have on the completeness rate for your state.
  3. Evaluation of the number of cases in your registry with residences in other states to determine the states that may want to share your data.
- B. Guidelines for release of data.
- C. Guidelines for use of exchanged data.
- D. Procedure for termination of case-sharing agreements.
- E. Method for amending case-sharing agreements.
- F. Review and signature requirements for new case-sharing agreements.

#### **M 2. Methods used to transmit data to other states**

*Describe:*

- A. Data definitions for files.
- B. Exchange media.
- C. Data exchange format.
- D. Edit requirements.
- E. Virus detection methods.
- F. Disk labeling.

#### **M 3. Methods used to accept data from other states**

- A. Data definitions for files.
- B. Exchange media.
- C. Exchange format.
- D. Edit requirements.
- E. Virus detection methods.
- F. Disk labeling.

#### **M 4. Confidentiality issues**

*Describe methods used to re-release data received through data exchange.*

- A. Nonconfidential format.
  1. Aggregate reports and public data sets.
  2. Cases submitted to NAACCR, SEER, or NPCR.
- B. Confidential format.
  1. Researchers.
  2. Response to subpoena.

#### **M 5. Method and schedule for evaluating impact of case sharing**

*Describe the method used to calculate the percentage of unduplicated cases added to the registry through case sharing.*

**Priority**

- M 6. Copy of sample case-sharing agreement**
- M 7. List entities with whom the registry has case-sharing agreements**
- M 8. Staff position assigned as case-sharing contact**

See NAACCR Standards for Cancer Registries, Volume III, Section I.B.5: Out-of-State/Province Coverage, Case Sharing and Coverage of Nonresidents.

**References**

NAACCR. Standards for Cancer Registries, Volume III. Standards for Completeness, Quality, Analysis, and Management of Data. Springfield, IL: North American Association of Central Cancer Registries, September 2000.

NAACCR. Procedure Guidelines for Cancer Registries, Series I. Inter-State Data Exchange. Springfield, IL: North American Association of Central Cancer Registries, June 1999 (original release).

## Section 8: Quality Control

### Priority

#### **H 1. Quality assurance plan**

*Quality assurance plan may include:*

- A. Description of activities for monitoring quality.
  1. Checks on case ascertainment.
  2. Checks on data quality.
- B. Documentation of the quality control procedures performed.
- C. Documentation for each of the job tasks within the section.
  1. List of case ascertainment sources, such as pathology, hematology, cytology, disease index, autopsy, oncology, radiation therapy, other.
  2. List of data quality sources, such as abstracted data compared with source documents and/or medical record.
- D. Documentation of the rules and guidelines used by the technical staff to reconcile edits and/or discrepancies (e.g., SEER rules used for resolution of multiple primaries, ROADS coding rules used).

#### **H 2. Initial abstract processing**

*Describe:*

- A. Case receipt log and document whether it is maintained manually or computerized.
- B. Correlation of number of cases submitted.
- C. Notification of receipt of cases to reporting facility.
- D. Visual review of submitted data before addition to the database and description of criteria for case review.
  1. All cases reviewed or a percentage of cases reviewed.
  2. All or selected data elements reviewed.
- E. Mechanism to review codes in conjunction with documentary text.
- F. Data items routinely verified before addition to the database.
- G. Use of data edits.

*State whether all records or only specific data fields are edited.*

#### **H 3. Computer edits**

*Describe:*

- A. Edit programs used and indicate whether EDITS is used, the programs are provided by a commercial vendor, or the programs are developed in-house. If EDITS is used, is the NAACCR or ACoS metafile being used?
- B. Frequency and timing of editing.
- C. Edit resolution, including the acceptable percent error rate above which you will not process the data for submission.
- D. Statistical process control thresholds.
- E. Error reports.
  1. Frequency with which the reports are created.
  2. Format, which may include:
    - a. Percentage of case reports with edit errors by facility.
    - b. Number of edits that triggered any edit error by facility.
    - c. Edit error summary: a summary of the detailed listing of each case with errors by type of error message.

**Priority**

- F. Use of an edits program other than your usual initial processing edits.
- G. Use of inter- and intrafield edits on data received through case-sharing agreements.

See NAACCR Standards for Cancer Registries, Volume III, Section II.A.4: Edits and Data Processing Capabilities for Data Quality; and Section II.B.1.b(3): Standards for Data Edits.

**H 4. Visual editing**

*Describe:*

- A. Percentage of cases reviewed.
- B. Selection criteria for cases reviewed, which may include those based on:
  - 1. Edit checks.
  - 2. Rule and guideline changes.
  - 3. Reporter experience.
  - 4. Previous reporting history.
- C. Fields edited.
- D. Resolution of errors, which may include:
  - 1. Automatic correction rules, such as specific codes replace unknown or blank codes.
  - 2. Notification of data changes to reporting facilities.
  - 3. Methods to contact reporters for resolution of conflicting information, such as phone calls or automatic reports.
- E. Error reports.
  - 1. Frequency with which the reports are created.
  - 2. Format, which may include:
    - a. Error summary report: number and percentage of cases from those received that had any errors detected on visual review by facility for a designated time period.
    - b. Batch summary report: listing of the number of errors found for specific data items such as stage, morphology, or grade.

See NAACCR Standards for Cancer Registries, Volume III, Section II.B.3: Quality Control Activities.

**H 5. Reconciliation of processing and editing discrepancies**

*Describe procedures for:*

- A. Reconciliation of database inter- and intrafield discrepancies.
- B. Correction of discrepancies.

**H 6. Guidelines for consolidation**

*Describe procedures for:*

- A. Error resolution.
- B. Management reports of workload measures, which may include:
  - 1. Total number of case reports processed.
  - 2. Ratio of case reports to tumors.
  - 3. Ratio of tumors to patients.
- C. Facility followback, which may include:
  - 1. Inconsistency reports.
  - 2. Information from case merges.

**Priority****H 7. Other quality assurance activities**

*Topics may include:*

- A. Facility reporter training.
- B. Training workshops.
- C. Quality control topics presented at local registrar organization meetings.
- D. Quality control articles or tips included in newsletters.
- E. Frequently asked questions posted on Web site.
- F. Log maintained of questions asked and response given to ensure consistency.

**H 8. Reabstracting audits**

*Describe:*

- A. List of reporting sources that are included in reabstracting studies.
- B. Eligibility criteria and study population.
- C. Sampling strategy for facility selection such as the percentage of facilities involved in reabstracting studies on an annual basis.
- D. Frequency of audits.
- E. Methods.
  1. How cases for reabstracting studies are selected.
  2. Determination of the number of cases to be reabstracted at a facility.
  3. Data items included in reabstracting studies.
- F. Analysis plan.
  1. Use of major and minor error levels.
  2. Levels of administration involved in audit.
  3. Use of mediator for reconciliation of differences.
  4. Documentation of rules and guidelines.
  5. Interaction and feedback.
  6. Method of calculation of error rates.
- G. Followback.
  1. Identification of problems.
  2. References used.
  3. Level of documentation on abstract.
  4. To whom followback is provided.

See NAACCR Standards for Cancer Registries, Volume III, Section II.B.3: Quality Control Activities; and Section II.C.1: Reabstracting and Recoding Audits.

**M 9. Special database quality control projects and studies**

*These may include:*

- A. Recoding studies.
  1. Percentage of cases recoded.
  2. Case selection criteria.
  3. Establishment of correct answers.
  4. Monitoring problems identified.
  5. Documentation of individual performance.
- B. Abstracting and coding reliability studies.
  1. Studies using the test-case method, such as comparing abstracts to preestablished codes.

**Priority**

2. Distribution of sample cases to:
  - a. Reporting facilities.
  - b. Central registry staff.
- C. Other quality control activities, which may include:
  1. Evaluation of missing or unknown data.
  2. Review of all individual data elements to verify validity, completeness, and usefulness.
- D. Protocol to identify unresolved duplicates.
- E. Evaluation of interfield reliability, which may include:
  1. Comparison of behavior to stage.
  2. Primary site and histology comparison for lymphoma and leukemia.
- F. Review of reports to evaluate the validity of multiple primary sites for the same patient.
- G. Provision for written, facility-specific results of quality control activities.
- H. Methods of corrective action used to address problems identified through quality control activities, such as implementation of fines or restrictions as required by legislation or regulations.
- I. Recognition awards to reporting facilities such as certificates for timeliness, completeness, and/or quality data.
- J. Educational programs for reporting facility personnel with instruction on identified problems.

See NAACCR Standards for Cancer Registries, Volume III, Section II.B.3: Quality Control Activities; and Section II.C.1: Reabstracting and Recoding Audits.

**References**

NAACCR. Standards for Cancer Registries, Volume III. Standards for Completeness, Quality, Analysis, and Management of Data. Springfield, IL: North American Association of Central Cancer Registries, September 2000.

NAACCR. Instructional Module for Cancer Registries. Cancer Registry Management Reports: Design and Implementation. Springfield, IL: North American Association of Central Cancer Registries, June 1998.

**Other Resources**

NAACCR. Report from the Non-Hospital Audit Protocol Work Group to NAACCR. Springfield, IL: North American Association of Central Cancer Registries, January 1999.

## Section 9: Followup

### Priority

- L 1. Staff position responsible for obtaining followup information**
- L 2. Definition of cases requiring followup**
- L 3. Process for followup, including whether the process is manual or computerized**
- L 4. Timeframe for followup**  
*Example: Annually*
- L 5. Methods used to perform followup, which may include:**
  - A. Active.
    - 1. Sources used.
    - 2. Order in which sources are contacted.
  - B. Passive.
    - 1. Sources used.
    - 2. Procedures for obtaining data.
- L 6. Casefinding suspense files used to update cases for followup**
- L 7. Formula used to calculate followup success rate, such as the ACoS-COC or SEER formula**
- L 8. Diagnoses included for followup**  
*Indicate whether all in situ cases except carcinoma in situ of the cervix are followed.*
- L 9. Sharing followup information**  
*Indicate whether followup information is shared with other central registries or with reporting facilities. Information shared may include:*
  - A. Copies of death certificates.
  - B. Followup information on living patients obtained from other facilities or from external linkages, such as with the Motor Vehicle Department or Voter Registration records.

See NAACCR Standards for Cancer Registries, Volume III, Section I.B.13: Patient Followup; and Section I.C.7: Followup Success Rates.

### References

NAACCR. Standards for Cancer Registries, Volume III. Standards for Completeness, Quality, Analysis, and Management of Data. Springfield, IL: North American Association of Central Cancer Registries, September 2000.

NAACCR. Instructional Module for Cancer Registries. Cancer Registry Management Reports: Design and Implementation. Springfield, IL: North American Association of Central Cancer Registries, June 1998.

## Section 10: Reports From Central Registry Data

### Priority

#### **M 1. Standards for reports**

*Describe:*

- A. Sources used for population data.
- B. Interpretation of population estimates.
- C. Suppression of nonconfidential data for summary statistics.
- D. Statistical methods used.
- E. Data display standards.

See NAACCR Standards for Cancer Registries, Volume III, Section III.A.2: Population Data.

#### **H 2. Annual reports**

*Describe:*

- A. Contents, which may include:
  1. Summary of central cancer registry data.
  2. Incidence rates, mortality rates, and survival rates.
  3. Levels used to compute rates.
  4. Levels used to release rates for public use.
    - a. Computing rates using different standard populations, such as 2000 U.S., 1970 U.S., 1940 U.S., World, Canadian.
    - b. Computing rates for multiple years such as 1987–1993 or 1991–1993.
    - c. Computing rates by grouping multiple counties and/or regions.
- B. Distribution.
  1. Method of distribution such as hardcopy, electronic copy, or Web site.
  2. Distribution list, which may include all reporting facilities, legislators, and/or registry liaisons.

See NAACCR Standards for Cancer Registries, Volume III, Section III.B: Data Analysis and Reporting: Process Standards.

#### **M 3. Facility reports**

*Describe:*

- A. Schedule such as how often and when reports are distributed.
- B. Types of reports produced, which may include:
  1. Summary of cases reported.
  2. Summary of nonconfidential statewide data.
  3. Edit reports, error reports, death clearance reports, followup reports.

#### **M 4. Special reports**

*Describe how special requests are processed.*

- A. Nonconfidential data requests.
  1. General requests including those from the media and lay public.
  2. Web site reports.
  3. Legislative reports.

**Priority**

- B. Confidential data requests.
    - 1. Protocol for access to confidential data.
    - 2. Internal Review Board (IRB) requirements.
  - C. Fees, charges, or costs for special/*ad hoc* data requests.
- M 5. Other reporting mechanisms**  
*These may include:*
- A. Newsletter.
    - 1. Schedule for publication such as monthly or quarterly.
    - 2. Distribution list.
  - B. Reports on special topics such as specific cancer sites, geographic areas, or special populations.
- M 6. Other data uses**  
*These may include:*
- A. Program planning.
  - B. Program evaluation.
  - C. Projections.
  - D. Rates and frequencies.
  - E. Survival.
  - F. Other.

**References**

NAACCR. Standards for Cancer Registries, Volume III. Standards for Completeness, Quality, Analysis, and Management of Data. Springfield, IL: North American Association of Central Cancer Registries, September 2000.

NAACCR. Instructional Module for Cancer Registries. Cancer Registry Management Reports: Design and Implementation. Springfield, IL: North American Association of Central Cancer Registries, June 1998.

## Section 11: Confidentiality

### Priority

- H 1. **Confidentiality forms for registry staff, including renewal frequency**
- H 2. **Policies for access to confidential data**
  - A. Definition of confidential data.
  - B. Registry responsibilities.
  - C. Copies of the application for access.
- H 3. **Process for reviewing confidential data requests**
- H 4. **Release of confidential data to scientific investigators**
- H 5. **Review of research results**
- H 6. **Patient contact for participation in epidemiologic studies**
- H 7. **Data security**
  - A. Access to physical location.
  - B. Access to data.

See NAACCR Standards for Cancer Registries, Volume III, Section I.B.8: Confidentiality Policies and Procedures: Issues in Data Collection and Management; and Section III.A.1: Confidentiality Policies and Procedures: Issues in Research, Reporting and Release of Data.

### Reference

NAACCR. Standards for Cancer Registries, Volume III. Standards for Completeness, Quality, Analysis, and Management of Data. Springfield, IL: North American Association of Central Cancer Registries, September 2000.

### Other Resources

Data Use and Confidentiality Task Force Report to NAACCR. Springfield, IL: North American Association of Central Cancer Registries, December 1999.

NAACCR Policy Statement 99-01: Confidentiality. Springfield, IL: North American Association of Central Cancer Registries, November 1999.