

PROCEDURE GUIDELINES FOR CANCER REGISTRIES



Registry Operations Committee

Comments and suggestions on this and other NAACCR documents are welcome. Please send your comments to the editor or any member of the NAACCR Board of Directors.

The completed series *Procedure Guidelines for Cancer Registries* are:

Series I: Interstate Data Exchange1

This document is intended for use by the operations staff of a population-based cancer registry who are involved in the exchange of cancer patient information with other cancer registries.

Original release: December 1999
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Series II: Calculating the Death Certificate Only (DCO) Rate22

This document is intended as a guide for what to include when calculating DCO rates.

Original release: June 2000

Series III: Preparing a Policy and Procedure Manual30

This document is intended for use by the staff of a population-based cancer registry as a guide to preparing a detailed policy and procedure manual for the operation of the registry.

Original release: January 2001

In the course of writing this document, the decision was made to avoid reference to a specific version of the NAACCR Data Exchange format, because it changes almost every year. The Registry Operations Committee thought that listing a specific version would make this current document obsolete in the very near future.

Copies of all standards documents can be viewed or downloaded from NAACCR's World Wide Web site at www.naacccr.org. For additional paper copies, write to the NAACCR Executive Office at 2121 West White Oaks Drive, Suite C, Springfield, IL 62704.

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SERIES I

**INTERSTATE
DATA EXCHANGE**



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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 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 timeliness, quality control, 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 data exchange among central cancer registries.

A population-based cancer registry must include all cancers occurring in residents of its coverage area, regardless of where the cases are diagnosed and/or treated. Without data exchange, cases migrating outside a state, province, or territory for cancer care may not be counted in population-based statistics, either within a central registry or within a regional or national database.

The identification of residents diagnosed in other areas is essential for complete population-based reporting. Collection of these cases from other registries is possible because of the standardization of data elements as promulgated by NAACCR. Additionally, individual hospitals and pathology laboratories often exchange data to obtain complete coverage. Incomplete case ascertainment in population-based cancer registries can have an effect on the accurate assessment of the cancer burden in a state, province, or territory. Accurate and complete data will enable each registry to assess cancer incidence among its population and also enable more accurate assessments for the U.S. and Canadian populations.

Several issues related to data exchange have been identified. These include the identification of the states, provinces, and territories for exchange; the data exchange format; the quality of exchanged data; and the timeline for data exchange. These issues will be discussed in greater detail in this series.

Evaluating the Impact of Completeness, Timeliness, and Data Quality

Before undertaking an exchange of data, a cancer registry should evaluate the receipt of resident cases in the context of completeness, timeliness, and data quality.

Discussion: Completeness

Interstate exchange of cancer data has various levels of importance to population-based registries in accurately assessing incidence rates for the state, province, or territory. Without these data exchange efforts, patients who migrate outside the reporting area for cancer diagnosis and care will not be counted in any population-based statistics. For some cancer registries, incomplete case ascertainment can have a detrimental effect on assessment of the cancer burden in the reporting area. Conversely, some population-based registries find that the addition of exchange data to their registry does not affect the cancer incidence rate enough to warrant the time involved in processing and merging the cases.

Before establishing a data exchange agreement, the cancer registry should:

1. Evaluate cancer care patterns.
 - a. Do patients travel out of the reporting area to a major cancer center?
 - b. Do certain types of cancer patients seek care out of the state, province, or territory (e.g., children, certain racial or ethnic groups, or patients with a particular cancer diagnosis)?
 - c. Where are the magnet centers located?
2. Compare cancer incidence rates either to national incidence rates or to projected state, territory, or provincial rates. Evaluate the potential impact of data exchange on cancer incidence rates by evaluating the following:
 - a. Are registry site-specific cancer rates lower than comparable national rates?
 - b. Does the addition of incidence cases from another registry impact the incidence rates in the receiving registry?
3. Conduct an evaluation of incidence rates for counties and bordering or neighboring states, provinces, or territories.
 - a. Are border county cancer rates lower than comparable state rates?
 - b. Would the addition of incidence cases from another state change the incidence rates in border counties?
 - c. Are there areas in the state, province, or territory that might be affected by a large cancer center or cancer care facility located in another part of the country?

In some population-based registries, the percentage of cases received from data exchanges may not change the overall completeness, assuming that all other reporting sources are complete. For example, an overall change of 0.5 percent may not seem significant if the registry is already 98 percent complete (the NAACCR gold standard for completeness is 95 percent). However, the percent change in a border area might be more significant, thus influencing the decisions regarding data exchange. If all or more of the percent change is located in a single county or area, these data would be incomplete and unreliable if the exchanged data were not included.

Evaluating the Impact of Completeness, Timeliness, and Data Quality (continued)

Outmigration for cancer care for late-stage disease or for treatment of cancer also may affect overall incidence rates. See Appendix A for examples of methods used to evaluate the impact of data exchange on completeness of reporting.

Discussion: Timeliness

The timely submission of cancer incidence reports to the cancer registry is essential to achieve the goal of providing quality cancer data. Many of the major standard-setting organizations have established guidelines for reporting.

1. **American College of Surgeons:** Cases must be abstracted within 6 months of initial diagnosis.
2. **Surveillance, Epidemiology, and End Results Program (SEER):** The registry must be able to provide complete counts of new cases for a calendar year within 20 months of the end of that calendar year.
3. **Centers for Disease Control and Prevention/National Program of Cancer Registries (CDC/NPCR):** Within 12 months of the close of the diagnosis year, 90 percent of expected, unduplicated cases are available to be counted as incident cases at the central cancer registry.
4. **North American Association of Central Cancer Registries (NAACCR):** Standards for Cancer Registries, Volume III: Standards for Completeness, Quality, Analysis and Management of Data. Within 18 months of the close of a diagnosis year, the registry should contain at least 95 percent of the expected cases of reportable cancer occurring in residents during that year.

Standards

Data exchange should be completed within a timeframe that allows registries to include received cases in their annual report, the NAACCR call for data file, and the NAACCR certification file. Thus, the date of exchange should be no later than July of the subsequent year of diagnosis.

Evaluating the Impact of Completeness, Timeliness, and Data Quality (continued)

Discussion: Data Quality

Quality control is an important operational activity for any cancer registry. The reliability, validity, and completeness of the data must be of excellent quality to ensure that the incoming and outgoing data can be added to the respective databases.

Three major quality control issues have caused significant problems for many registries engaging in data exchange: (1) blank and unknown data fields; (2) number of reports for each tumor (i.e., either consolidated or source records); and (3) nonstandard data definitions and codes.

Blank and unknown data fields

Because population-based cancer registries collect varying amounts of cancer diagnostic, treatment, and followup information, problems may be encountered when the sending registry does not collect the same information as the receiving registry. For example, if an incidence-only registry sends exchange data to a SEER registry, many of the NAACCR data exchange fields related to followup, extent of disease staging, and other variables may be blank. This will create problems for the SEER registry because it may be required to “fill in the blanks” before loading the file onto its database. The NAACCR Standards for Cancer Registries, Volume II: Data Standards and Data Dictionary, Version 8, Chapter X Introduction states:

A program that generates a file of records in the NAACCR data exchange format should handle instances where information is unavailable for any given field. A general rule follows: When **all** of the records in the file to be generated contain no information on a specific data item, then the corresponding columns in the exchange record should be left blank. When some of the records contain information for a given field, and other records will not contain information for that field, then the code that indicates ‘unknown’ or ‘not applicable’ must be written in the corresponding columns in the exchange record.

See the examples on page 63 of NAACCR’s Data Standards and Data Dictionary, Version 8.

Number of records for each tumor

The sending and receiving registries should determine whether they want all source records for each tumor or only the consolidated record. This should be defined clearly in the exchange agreement. Nonconsolidated records will require significantly more time for the receiving registry to process and clean up; however, use of nonconsolidated records may permit exchange in a more timely fashion. If only consolidated records are exchanged, the exchange file should be checked for duplicate records, and all duplicates should be deleted.

Evaluating the Impact of Completeness, Timeliness, and Data Quality (continued)

Nonstandard data definitions and codes

NAACCR's Data Standards and Data Dictionary contains the accepted codes for exchange of cancer data. Codes for data items for which standards have not been established are to be collected in state-specific fields as stated in the Data Standards and Data Dictionary. **These nonstandard codes should not be included in a data exchange.**

The quality control activities listed below should be followed when sharing cases with other cancer registries.

Standards: Outgoing

1. Run a virus check on all diskettes.
2. Make sure all cases are residents of the state, province, or territory with whom you are sharing data.
3. Remove duplicate cases from the file if you are sending consolidated records.
4. Run the NAACCR EDITS metafile and correct errors before sending the disk to the sharing state, province, or territory.
5. Include an electronic copy of the file layout with the disk.
6. Flag each case as it is exchanged. This may be done manually by recording information in a log, or electronically by applying a flag to a state-specific field within the central registry database. There is an existing NAACCR data item called "Date Case Report Exported (2110)" that is not currently well defined for use by a central registry.

Standards: Incoming

1. Request registry-specific or nonstandard data definitions from registries involved in case sharing.
2. Run a virus check on all diskettes.
3. Specify the NAACCR case record type and the version of the data exchange record layout.
4. Screen the data submitted for completeness and accuracy using the NAACCR EDITS metafile.

Exchange Media

Discussion

Data may be exchanged between central registries through a variety of media:

1. Electronic data files via secure e-mail, on diskette, or on CD-ROM.
2. Copies of paper abstracts.
3. Printed reports generated from computer systems.

Electronic data transfer is the preferred method of exchange.

Standards

All exchanged data must include:

1. The NAACCR case record type and the version of the data exchange record layout.
2. The name of a contact person for any problems encountered with a data submission.
3. An information sheet from the submitting registry that includes the registry name, a count of the cases included, the date the file was created, the name of the file, and the range of diagnosis dates included.

Data Encryption

It is strongly encouraged that all confidential data be encrypted before any nonsecure electronic exchange or transmission of data. This becomes more important as an increasing number of reporting facilities and state, provincial, and territorial cancer registries are utilizing the Internet and e-mail for exchanging confidential data. Multiple encryption software packages are available. Currently, NAACCR is using PGP encryption software for the Call for Data. The Chair or members of the Information Technology Committee of NAACCR can be contacted for more information on available encryption software.

Exchange Format

Discussion

The registries involved in data exchange should agree to provide case information on a nonresident to the population-based registry covering the patient's place of residence. The shared information should include confidential and nonconfidential data and abstracted text summaries (NAACCR case record type A), using the approved definitions as described in the most recent version of NAACCR's Data Standards and Data Dictionary.

NAACCR summarizes the requirements and recommendations for collection of each data item through standard-setting groups. NAACCR case record type A refers to NAACCR's recommendations for collecting incidence data plus treatment, detailed staging, and followup. The most recent data exchange version should be used to avoid problems with code conversions. Use of the standard format for exchange of data means that each registry's computer system needs to read and write in this format. Registries that are unable to exchange in the most recent format should specify their exchange requirements in the exchange agreement.

Standardization of the data exchange information improves the quality of merged files and facilitates data exchange.

Standards

1. Data files submitted for data exchange with another registry must be standardized using NAACCR data items, codes, and record layout.
2. The data files must be submitted in machine-readable format and transmitted to the other registry by modem, secure Internet connection, CD-ROM, or floppy diskette.
3. The data file must be submitted in the most recent version of the data exchange record layout and contain an appropriate level of patient and case identification to allow for appropriate merging with registry files (NAACCR record type A).
4. Item #50, column 19-19, NAACCR Record Version, must be completed for each submission.
5. Item #450, column 238-238, Site Coding System—Current, must be completed for each submission.
6. Item #1460, column 635-635, RX Coding System—Current, must be completed for each submission.

Confidentiality Issues Related to Case Sharing

Discussion

Confidentiality policies and procedures are required in all phases of population-based cancer registry operations to protect the privacy of the individual patient, to protect the privacy of the facilities reporting the cases, to provide public assurance that the data will not be abused, and to abide by any confidentiality-protecting legislation or administrative rules that may apply.

Re-release of exchanged record information in a nonconfidential format

Because the purpose of the exchange is to add incident information to the receiving registry database and to increase the percentage of case completeness, it should be acknowledged in the exchange agreement that the incoming records will be included in any aggregate report or file (including public data set files). Additionally, it should be acknowledged that the exchange data will be included in any submission of cases to NAACCR for the Call for Data or for NAACCR certification.

Release of exchanged record information in a confidential format

Many of the concerns inherent in the exchange of data are focused on either the re-release of exchanged data to requesters or release through subpoena. The submitting registry should always be notified if the cancer incidence case is re-released under subpoena, for use in an approved research project, or to someone outside the receiving registry. The notification procedure should be clearly stated in the exchange agreement.

If the statute of the submitting state, province, or territory prohibits the secondary release of cancer patient information, *this must be clearly stated in the exchange agreement*. The submitting registry should request documentation of the method used by the receiving registry to ensure that these cases are not released.

Case-Sharing Agreements

Discussion

Once the two registries have agreed to exchange data, a formal agreement should be developed to cover the following:

1. Identification of exchange format.
2. Provisions for confidentiality.
3. Guidelines for use of the exchanged data.
4. Guidelines for release of information to third parties.
5. Modification of individual items specific to the provincial/state/federal government or agency law.
6. Methods required for subsequent amendments to the agreement.
7. Details on how the agreement may be terminated.
8. Identification of a key contact at each registry who will be responsible for processing the exchange.

Agreements will differ on a case-by-case basis; however, a sample case-sharing agreement is shown in Appendix B and may be used as a guide to develop registry-specific agreements.

Depending on laws governing the individual cancer registry, reciprocal agreements may be required.

Data Exchange Checklist for Outgoing Case Sharing

- 1. The exchange file is prepared in the latest version of the data exchange record layout and contains NAACCR case record type A.
- 2. All cases are residents of the state, province, or territory to which the data are being sent.
- 3. Documentation is included that identifies the file as containing either consolidated or nonconsolidated records (depending on the definitions outlined in the exchange agreement).
- 4. The NAACCR EDITS metafile program has been run on the file, and the errors have been corrected.
- 5. A virus check has been run on the entire file.
- 6. The data exchange file diskette is labeled with the name of the submitting cancer registry, the count of cases included, the date the file was created, the name of the file, the reporting period, and the format type.
- 7. All nonstandard data definitions and codes have been converted, and state-specific variables have been removed from the file.
- 8. The mailing address and contact person have been verified.

Series I Appendices

Evaluating the Impact of Completeness

The Illinois State Cancer Registry (ISCR) has evaluated the impact of data exchange on the completeness of their cancer registry and found an overall increase of 5.8 percent for 1990–1992 when the out-of-state data were added. No overall evaluation of the impact of data exchange has been performed since that time because of significant delays in reporting with some of the exchange states. Of 15 states with whom Illinois has developed an agreement, one state accounts for 44 percent of the records received through data exchange (> 2.8 percent of the overall incidence). If a state is experiencing delays in reporting or exchange, the impact on data completeness can be significant.

Interestingly, upon evaluation of the impact on border counties, it was discovered that out-of-state reports accounted for 30 to 90 percent of the cancer incident cases for some individual counties.

The attached tables and map were developed by ISCR and are offered as examples for evaluating data exchange impact within your state, province, or territory.

Figure 1. Illinois Counties With Out-of-State Urban Centers.
Identifying large out-of-state medical centers can assist with decisions about states to contact for exchange.

Table 1. Data From 3 Years of Complete Out-of-State Reporting.

Table 2. Cancer Incidence by Age Group and Report Type.

Figure 1.
Illinois Counties With Out-of-State Urban Centers

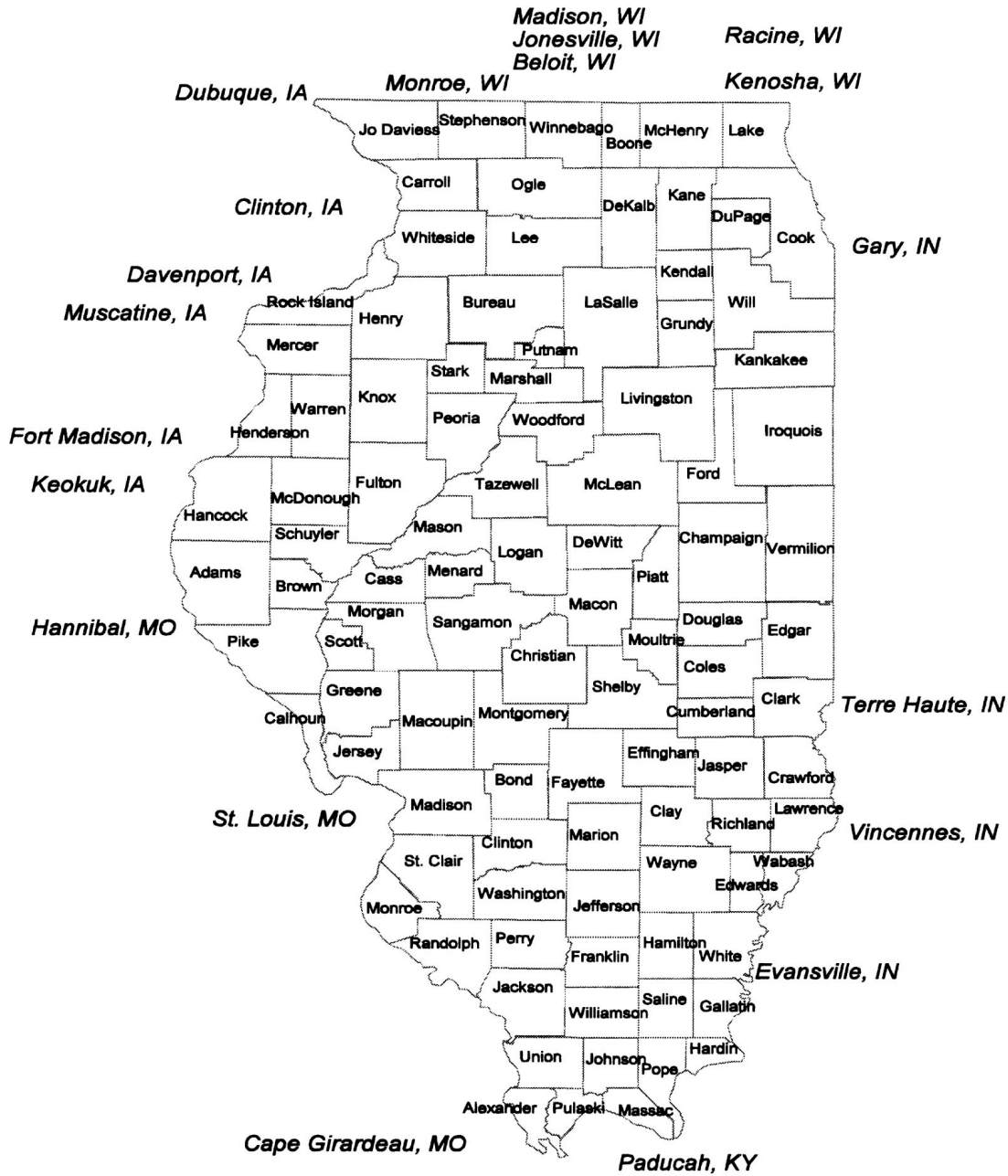


Table 1.
Data on 1990–1992 Cancer Incidence by Type of Reporting
From the Illinois State Cancer Registry, January 1999

County	Reported by Instate Facilities	Received From Out-of-State Exchanges	DCO	Total	Percent Reported by Instate Facilities	Percent Received From Out-of-State Exchanges	Percent DCO*	Percent Total
Adams	1084	94	1	1179	91.9	8.0	0.1	100.0
Alexander	22	152		174	12.6	87.4		100.0
Bond	155	44		199	77.9	22.1		100.0
Boone	336	8		344	97.7	2.3		100.0
Brown	85	2		87	97.7	2.3		100.0
Bureau	497	50		547	90.9	9.1		100.0
Calhoun	93	17		110	84.5	15.5		100.0
Carroll	188	114		302	62.3	37.7		100.0
Cass	207	5		212	97.6	2.4		100.0
Champaign	1652	48	4	1704	96.9	2.8	0.2	100.0
Christian	644	6	1	651	98.9	0.9	0.2	100.0
Clark	88	120		208	42.3	57.7		100.0
Clay	178	36		214	83.2	16.8		100.0
Clinton	428	89	1	518	82.6	17.2	0.2	100.0
Coles	638	13	1	652	97.9	2.0	0.2	100.0
Cook	65172	1283	36	66491	98.0	1.9	0.1	100.0
Crawford	118	174		292	40.4	59.6		100.0
Cumberland	145	4		149	97.3	2.7		100.0
DeKalb	733	26	2	761	96.3	3.4	0.3	100.0
DeWitt	258	1		259	99.6	0.4		100.0
Douglas	274	6		280	97.9	2.1		100.0
DuPage	8469	61	6	8536	99.2	0.7	0.1	100.0
Edgar	252	79	2	333	75.7	23.7	0.6	100.0
Edwards	74	61		135	54.8	45.2		100.0
Effingham	441	15		456	96.7	3.3		100.0

Table 1.
Data on 1990–1992 Cancer Incidence by Type of Reporting
From the Illinois State Cancer Registry, January 1999 (continued)

County	Reported by Instate Facilities	Received From Out-of-State Exchanges	DCO	Total	Percent Reported by Instate Facilities	Percent Received From Out-of-State Exchanges	Percent DCO*	Percent Total
Fayette	366	35		401	91.3	8.7		100.0
Ford	235	2		237	99.2	0.8		100.0
Franklin	580	97		677	85.7	14.3		100.0
Fulton	630	18		648	97.2	2.8		100.0
Gallatin	45	63	1	109	41.3	57.8	0.9	100.0
Greene	251	9	1	261	96.2	3.4	0.4	100.0
Grundy	455	10		465	97.8	2.2		100.0
Hamilton	88	43		131	67.2	32.8		100.0
Hancock	229	121		350	65.4	34.6		100.0
Hardin	26	32		58	44.8	55.2		100.0
Henderson	42	80		122	34.4	65.6		100.0
Henry	629	74	1	704	89.3	10.5	0.1	100.0
Iroquois	537	12		549	97.8	2.2		100.0
Jackson	490	67		557	88.0	12.0		100.0
Jasper	150	11		161	93.2	6.8		100.0
Jefferson	424	96		520	81.5	18.5		100.0
Jersey	260	31		291	89.3	10.7		100.0
JoDaviess	142	261		403	35.2	64.8		100.0
Johnson	91	68		159	57.2	42.8		100.0
Kane	3306	25	3	3334	99.2	0.7	0.1	100.0
Kankakee	1493	13	2	1508	99.0	0.9	0.1	100.0
Kendall	396	4	1	401	98.8	1.0	0.2	100.0
Knox	804	58	1	863	93.2	6.7	0.1	100.0
Lake	5243	174	3	5420	96.7	3.2	0.1	100.0
LaSalle	1491	67	4	1562	95.5	4.3	0.3	100.0
Lawrence	100	218		318	31.4	68.6		100.0

Table 1.
Data on 1990–1992 Cancer Incidence by Type of Reporting
From the Illinois State Cancer Registry, January 1999 (continued)

County	Reported by Instate Facilities	Received From Out-of-State Exchanges	DCO	Total	Percent Reported by Instate Facilities	Percent Received From Out-of-State Exchanges	Percent DCO*	Percent Total
Lee	472	27	1	500	94.4	5.4	0.2	100.0
Livingston	552	11		563	98.0	2.0		100.0
Logan	467	3		470	99.4	0.6		100.0
McDonough	412	43		455	90.5	9.5		100.0
McHenry	1944	94	6	2044	95.1	4.6	0.3	100.0
McLean	1414	22	1	1437	98.4	1.5	0.1	100.0
Macon	1807	19	2	1828	98.9	1.0	0.1	100.0
Macoupin	700	63	1	764	91.6	8.2	0.1	100.0
Madison	2849	790	2	3641	78.2	21.7	0.1	100.0
Marion	633	104		737	85.9	14.1		100.0
Marshall	230	9		239	96.2	3.8		100.0
Mason	278	8		286	97.2	2.8		100.0
Massac	65	164		229	28.4	71.6		100.0
Menard	179	2		181	98.9	1.1		100.0
Mercer	203	43		246	82.5	17.5		100.0
Monroe	162	122		284	57.0	43.0		100.0
Montgomery	524	24	1	549	95.4	4.4	0.2	100.0
Morgan	466	10		476	97.9	2.1		100.0
Moultrie	217	4		221	98.2	1.8		100.0
Ogle	591	27		618	95.6	4.4		100.0
Peoria	2800	59	3	2862	97.8	2.1	0.1	100.0
Perry	278	63		341	81.5	18.5		100.0
Piatt	249	5		254	98.0	2.0		100.0
Pike	247	31		278	88.8	11.2		100.0
Pope	14	49		63	22.2	77.8		100.0
Pulaski	39	94		133	29.3	70.7		100.0
Putnam	79	9	1	89	88.8	10.1	1.1	100.0

Table 1.
Data on 1990–1992 Cancer Incidence by Type of Reporting
From the Illinois State Cancer Registry, January 1999 (continued)

County	Reported by Instate Facilities	Received From Out-of-State Exchanges	DCO	Total	Percent Reported by Instate Facilities	Percent Received From Out-of-State Exchanges	Percent DCO*	Percent Total
Randolph	385	107		492	78.3	21.7		100.0
Richland	189	60		249	75.9	24.1		100.0
Rock Island	2119	248		2367	89.5	10.5		100.0
St. Clair	2779	648	6	3433	80.9	18.9	0.2	100.0
Saline	233	164	1	398	58.5	41.2	0.3	100.0
Sangamon	2728	19	2	2749	99.2	0.7	0.1	100.0
Schuyler	114	5		119	95.8	4.2		100.0
Scott	87	1		88	98.9	1.1		100.0
Shelby	350	4		354	98.9	1.1		100.0
Stark	119	2		121	98.3	1.7		100.0
Stephenson	633	150	1	784	80.7	19.1	0.1	100.0
Tazewell	1675	27	5	1707	98.1	1.6	0.3	100.0
Union	129	134		263	49.0	51.0		100.0
Vermilion	1358	52	1	1411	96.2	3.7	0.1	100.0
Wabash	62	99		161	38.5	61.5		100.0
Warren	195	20	1	216	90.3	9.3	0.5	100.0
Washington	182	30		212	85.8	14.2		100.0
Wayne	178	60		238	74.8	25.2		100.0
White	82	213	1	296	27.7	72.0	0.3	100.0
Whiteside	681	210	2	893	76.3	23.5	0.2	100.0
Will	3645	71	6	3722	97.9	1.9	0.2	100.0
Williamson	674	98	3	775	87.0	12.6	0.4	100.0
Winnebago	3229	230	3	3462	93.3	6.6	0.1	100.0
Woodford	414	3		417	99.3	0.7		100.0
TOTAL OR MEAN	140845	8751	121	149717	94.1	5.8	0.1	100.0

*DCO rates for years 1990–1992 are low because the Illinois State Cancer Registry did not initiate death clearance until late in 1994.

Table 2.
Cancer Incidence 1990–1992 by Age Group and Reporting Type

Age at Diagnosis (yr)	In-State	Out-of-State	DCO	Total	Percent In-State	Percent Out-of-State	Percent DCO	Percent Total
Age Group 1								
0-19	1233	167	2	1402	87.9	11.9	0.1	100.0
20+	139612	8584	119	148315	94.1	5.8	0.1	100.0
Total	140845	8751	121	149717	94.1	5.8	0.1	100.0
Age Group 2								
0-14	853	137		990	86.2	13.8		100.0
15+	139992	8614	121	148727	94.1	5.8	0.1	100.0
Total	140845	8751	121	149717	94.1	5.8	0.1	100.0

Agreement for Exchange of Cancer Data Between the

_____ (name of submitting registry) _____

and the

_____ (name of receiving registry) _____

1. Services

By signing this agreement, the parties state their intention to exchange information concerning cancer patients who are residents of the other's state, province, or county. This exchange is based on the mutual assurance that the identifying information on the patient(s) exchanged are protected and shall be kept strictly confidential. This exchange does not pertain to any data collected as part of special morbidity or mortality studies or other research projects.

In addition, the parties agree to:

- a. Provide the information electronically in the most recent version of the NAACCR data exchange layout.
- b. Provide the data file in NAACCR case record type A.
- c. Provide the information within 20 months of the close of the diagnosis.
- d. Carefully restrict use of the information. The information is intended to be used for registry administration and for aggregated statistical tabulations and analyses.
- e. Restrict access to cancer incidence data or identifiable information on a cancer patient or health care provider that was supplied under the terms of the agreement from being released to anyone not employed in the direct operation of the recipient registry. Employees may include those involved in the processing, administration, quality control review, and the statistical surveillance of cancer incidence data.
- f. Notify the exchange registry if, in the conduct of approved research or other activities, there is release of a cancer patient's identifying information. Should such a release take place, the receiving registry will be notified in writing within 48 hours of the release of the data.
- g. Terminate this agreement immediately upon the written notification of either party to terminate the agreement.

2. Confidentiality

- a. The parties understand and agree that any and all data that may lead to the identification of any patient, research subject, physician, other person, or reporting facility is strictly privileged and confidential and agree to keep all such data strictly confidential.
- b. The parties further agree to require all officers, agents, and employees to keep all such data strictly confidential; to communicate the requirements of this section to all officers, agents, and employees; to discipline all persons who may violate the requirements of this section; and to notify the originating party in writing within 2 working days (48 hours) of any violation of this section, including full details of the violation and corrective actions to be taken.

- c. The parties further agree that all data provided under the provisions of this agreement may only be used for the purposes named in this agreement.
- d. In the event that either party receives a subpoena or other court order compelling disclosure of confidential data, the parties agree to notify the registry that initially provided the data within 2 working days (48 hours) of receipt of the subpoena or court order. Additionally, the parties agree that, should they receive such a subpoena, they shall take all legal steps reasonably necessary to oppose the subpoena.

3. Amendments

This agreement may not be amended without prior written approval of both parties to the agreement.

4. Assignment

The parties understand and agree that this agreement may not be sold, assigned, or transferred in any manner and that any actual or attempted sale, assignment, or transfer shall render this agreement null, void, and of no further effect.

5. Term

This agreement shall be in effect from the date of execution until terminated by either of the parties. Termination shall be in writing sent pursuant to Section 6.

6. Notices

All notices required or desired to be made by either party to this agreement shall be sent by certified mail to the following respective addresses:

(Provide address and contact for each party to this agreement.)

Signatures

(Provide name, title, agency, date, and appropriate signatures for each registry)

SERIES II

**CALCULATING THE
DEATH CERTIFICATE ONLY
(DCO) RATE**



**Edited by:
Registry Operations Committee
June 2000**

Series II: Calculating the Death Certificate Only (DCO) Rate

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Calculating the Death Certificate Only (DCO) Rate

The following information provides a general guide for calculating the DCO rate for a population-based registry. The information is presented in the form of an example.

Step 1: Match Death Records

- Match death records for a given year against **all** cancer registry data.
- Identify the cancer deaths that do not match a record in the registry.

For this example we will use $N = 500$, where N is the number of nonmatched deaths.

Step 2: Eliminate Nonreportable Cases

Eliminate (from the 500) any:

- Nonreportable cases.
- Deaths that were not caused by cancer but were coded as cancer.
- Out-of-state residents.
- Cancers diagnosed before the registry reference date.

For this example, we will assume that 50 cases are eliminated from the original nonmatched file:

$$500 - 50 = 450$$

Note:

- The nonmatched cancer deaths are those death certificates with cancer as a cause of death (any cause) that remain after the cancer registry match with the Vital Records death tape.
- These death certificates must then be reviewed to eliminate any cases that do not meet the criteria for an incidence case in your registry.
- Additionally, out-of-state residents are usually deleted from the death certificates that require more complete followback for clearance.

Step 3: Resolve Potential DCOs

- Use the remaining nonmatched cancer deaths to conduct death certificate clearance ($n = 450$) following your death clearance protocol.
- Through active clearance, eliminate cases from the potential DCO file by adding identified incident cases to the master cancer database file as a complete abstract.
 - These include cases not reported by routine sources but diagnosed since your registry's reference date: for example, physician-only cases, clinical diagnosis, nursing home cases, cases diagnosed or treated in other states, and cases missed by the reporting facilities.

For this example, we will subtract 200 cleared cases:

$$450 - 200 = 250 \text{ (true DCOs)}$$

Note:

- Nonmatched cancer deaths are cleared in a variety of ways, depending on the registry's ability to staff a DCO clearance program.
- Cleared death certificates may be identified in a variety of ways, including through letters to physicians, coroners, nursing homes, hospice centers and hospitals; linkage projects; or actual medical record review by registry staff.
- Depending on the death clearance procedure followed by the individual registry, abstracting of identified missed cases may be performed by the central registry field staff or by the reporting facility.
- Cases eliminated from the DCO file by transfer to the registry database become incidence cases if an actual (or approximate) diagnosis date is identified.
- Cases that are identified as missed by a reporting facility after followback should be added to the appropriate diagnosis year as actual incident records.
- True DCO cases = all remaining noncleared, nonmatched cancer death cases. **These include all potential DCOs that have not been fully resolved at the time the DCO rate is calculated.**

Step 4: The Formula

$$\left(\frac{\text{\# of true DCOs for the year}}{\text{total \# of cancer cases for the year}} \right) \times 100 = \text{DCO rate}$$

Where cancer cases = all unduplicated invasive cancers + in situ bladder cancers within the diagnosis year for state residents. These include all cases identified and abstracted from the death clearance project and all true DCOs. This information is included in the NAACCR Call for Data.

Step 4: The Formula—Example 1

Number (#) nonmatched cancer cases	500
Number (#) eliminated as not potential DCOs	- 50
Number (#) potential DCOs	450
Number (#) incident cases identified and abstracted after clearance (<i>your registry may identify these as missed cases</i>)	-200
(True DCOs	250)

Number (#) incident cases for a given year
plus (+) cases identified through clearance
plus (+) true DCOs
equals (=) total number of cancer cases for the year

Note:

In this example, the registry has 9,550 unduplicated cases from reporting and data exchange, 250 DCO cases, and 200 cases from the cleared (or missed) cases identified during death clearance, which equals 10,000 total incidence cases.

$$\left(\frac{250}{10,000} \right) \times 100 = 2.5\%$$

Where incident cases equals all unduplicated invasive cancers plus in situ bladder cancers within the diagnosis year for state residents. These include all cases identified and abstracted from the death clearance project and all true DCOs. This information is submitted as part of the NAACCR Call for Data.

Step 4: The Formula—Example 2

Number (#) nonmatched cancer cases	5,000
Number (#) eliminated as not potential DCOs	- 500
Number (#) potential DCOs	4,500
Number (#) incident cases identified and abstracted after clearance (<i>your registry may identify these as missed cases</i>)	- 1,345
(True DCOs	+ 3,155)
Number (#) incident cases for a given year	
<i>plus (+)</i> true DCOs	
<i>plus (+)</i> cases identified through clearance	
<i>equals (=)</i> total number of cancer cases for the year	

Note:

In this example, the registry has 63,859 unduplicated cases from reporting facilities and data exchange, 3,155 DCO cases, and 1,345 from the cleared (or missed) cases identified during death clearance, which equals 68,359 total incidence cases.

$$\left(\frac{3,155}{68,359} \right) \times 100 = 4.6\%$$

Where incident cases equals all unduplicated invasive cancers plus in situ bladder cancers within the diagnosis year for state residents. These include all cases identified and abstracted from the death clearance project and all true DCOs. This information is submitted as part of the NAACCR Call for Data.

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



**Edited by:
Registry Operations Committee
January 2001**

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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

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