SERIES I

INTERSTATE DATA EXCHANGE

Edited by:
Registry Operations Committee
January 2001

Series I: Interstate Data Exchange
Table of Contents

Introduction 2

Evaluating the Impact of Completeness, Timeliness, and Data Quality 3

Exchange Media 7

Exchange Format 8

Confidentiality Issues Related to Case Sharing 9

Case-Sharing Agreements 10

Data Exchange Checklist for Outgoing Case Sharing 11

Appendix A: Samples for Evaluating the Impact on Completeness 13

Appendix B: Sample Case-Sharing Agreement 20

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 sufficiently 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 provide 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

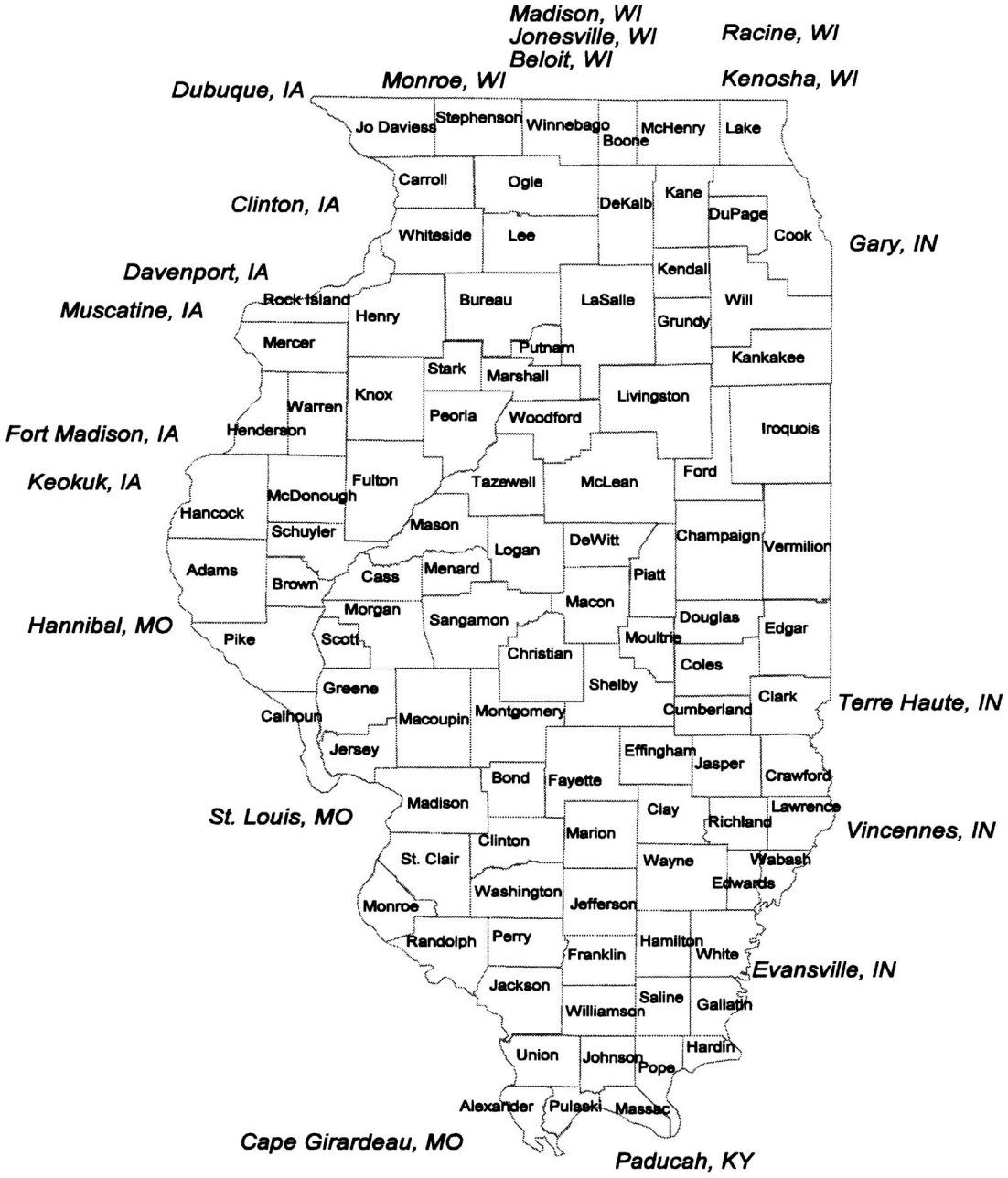

Table 1.
Data on 1990–1992 Cancer Incidence by Type of Reporting
From the Illinois State Cancer Registry, January 1999

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.

SAMPLE

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

SAMPLE

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)