

## POPULATION-BASED CANCER REGISTRIES IN THE UNITED STATES

The information for this report came from two sources: the 1993 publication of the American Association of Central Cancer Registries (AACCR), *Cancer Incidence in the United States, 1988-89*, and a telephone survey in September 1993 of other central, population-based registries in the U.S. that were operational in 1988, but elected not to be included in the AACCR publication. In 1988, 35 states and four metropolitan areas had a population-based registry. Information from 30 states and the four metropolitan areas was available for this analysis. Information from five states (Arizona, Kansas, Maryland, Minnesota, and Virginia) that did not participate in the AACCR publication could not be obtained during the time frame of the survey.

### General Comments on Cancer Registration in the United States

***Incidence only cf. full registry:*** Some registries, including all Surveillance, Epidemiology and End Results (SEER) registries, are full registries, meaning that they collect treatment and individual follow-up data. State-supported programs vary from being incidence only registries, with no treatment and no follow-up data, to full registry programs, and with every combination in between.

***Passive cf. active case ascertainment:*** Registries can be either an active or a passive system, the passive system being one whereby the registry relies upon cancer care facilities to report their cases. An active system, such as the SEER registries, has circuit riders, or abstractors, who go to facilities that diagnose or treat cancer patients and actively ascertain cases and case information.

***Levels of funding and funding source:*** SEER registries, although funds may be tighter than they have been in the past, are generally better funded for all aspects of registry operation than are state registries. They receive funds from the federal government, through the National Cancer Institute (NCI), in addition to partial support from their state, local university or some other organization. State registries are funded by individual states. Since funding levels vary widely, the extent of registration activities vary as well.

***Inter-state standardization of data collection:*** SEER data definitions and data elements are standardized across all sites; state registry definitions and data elements are not. The AACCR has recently completed recommendations, guidelines, and standards. Most registries have some form of data exchange program with neighboring states. However, the completeness of casefinding does vary and is affected by not only the completeness of case ascertainment and the quality of data in the neighbor registries, but also whether all neighboring areas have a registry and are able to exchange information with other central cancer registries (CCR).

***Reporting mandates are not the same among state registries:*** Cancer reporting is not part of the federal public health reporting system, but rather is determined by state mandates. Differences can include:

\* *Entities required to report:* In some states, cases diagnosed and treated in physician offices or other ambulatory settings are not required to report. Most require hospital reporting; others rely only on laboratory reporting.

\* *Reportability of tumors:* Registries use the International Classification of Diseases, Ninth Edition (ICD-9), ICD-9-Clinical Modification (CM), or the International Classification of Diseases for Oncology, First Edition (ICD -O) or Second Edition (ICD-O-2). However, the inclusion or exclusion of some sites may differ. For example, some require reporting of benign brain tumors, while others do not.

\* *Timeliness of reporting*: The mandate may specify how quickly the case must be reported to the central cancer registry, e.g., within six months of diagnosis, four months of hospital discharge, or perhaps no reporting time frame is defined. Some also state how often the reporting facility has to report cases: on a monthly basis, quarterly, once a year, or none is specified.

\* *Penalties for not reporting*: Some registries have penalties, others do not. The amount of the fines vary, when a fine exists. Some registry programs try to be creative and tie noncompliance with reporting to regulatory programs, like Certificate of Need (CON) applications or hospital accreditation. Even with penalties, policies about imposing fines on reporting facilities can vary.

\* *Quality assurance/quality control (QA/QC) requirements*: Mandates may require certain steps for quality assurance or certain types of quality control studies (e.g., re-abstract, reliability, case ascertainment completeness). Despite the mandate, QA/QC activities differ. The availability of resources often dictates the extent of quality checks, training, computer edits, and post-hoc quality assessment studies. The number and proportion of hospitals with cancer programs approved by the Commission on Cancer of the American College of Surgeons (ACoS) that report to the CCR can influence data quality (i.e., the more hospitals with an ACoS program, the higher the quality of the reported data, due to the ACoS requirement that data quality activities be performed). Accurate and complete data coming into the registry are the most cost-effective control for quality. Post-hoc studies are the most costly.

\* *Coverage (out-of-state residents)*: Legal restrictions may prohibit some registries from exchanging data with other states, while some mandates omit reporting of out-of-state residents to the CCR of that state. In recent years, these restrictions are disappearing and registries are actually becoming fairly uniform in this regard.

**Confidentiality and data access issues**: Every registry has their own policy, formal or informal, about access to confidential, and even to sensitive, data. It ranges from being written in the law or administrative rules and regulations to no release of confidential data under any circumstances.

### Administrative Descriptions of Cancer Registries in the United States

All 25 CCRs not in the SEER program are statewide registries (referred to in graphs as *State*). Of the nine SEER programs in 1988, four are bounded by county borders and five encompass entire states.

Figure 1 describes the administrative entities for SEER and state registries in 1988. There is more variety in the SEER program, whereas nearly all of the other CCRs are administered by a state agency, or a combination of a state agency and some other entity.

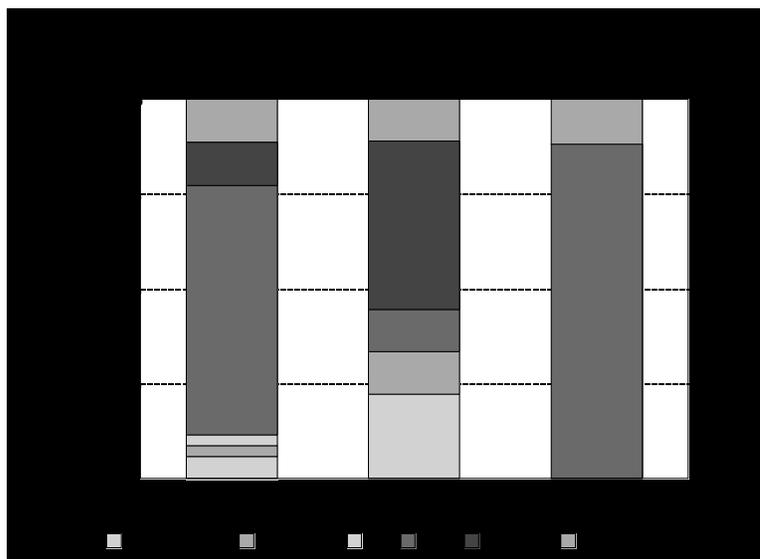
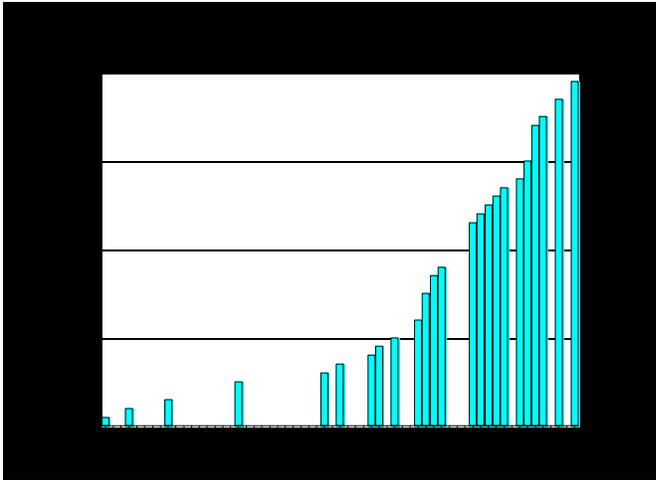


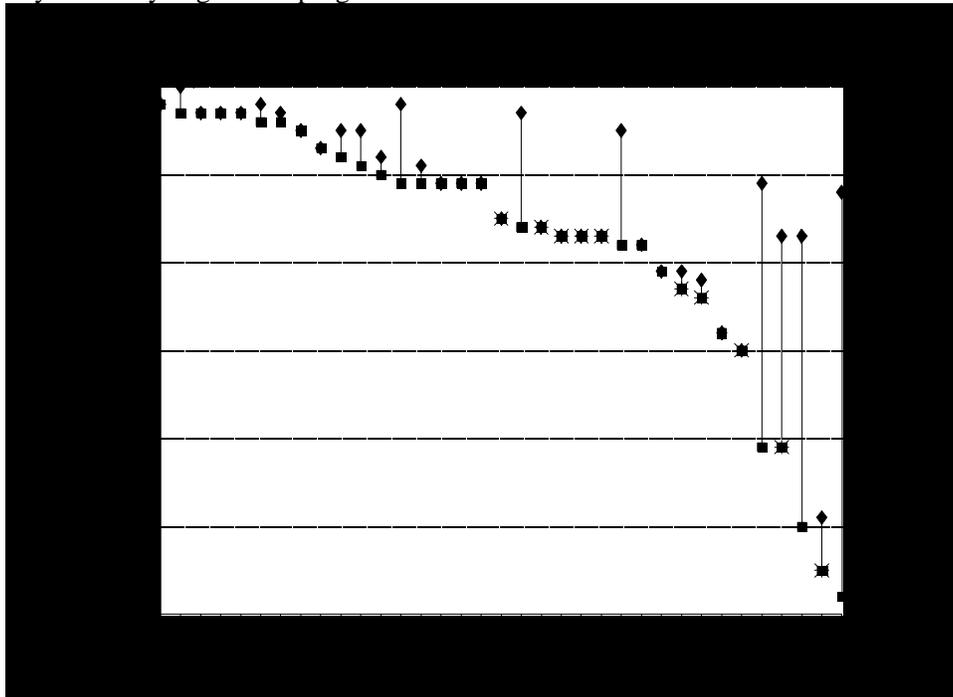
Figure 1: Administrative Entities for SEER and State Registries, 1988-89



**Figure 2: Cumulative Frequency by first Year of Operation**

The oldest registry reports it began in 1932, as shown in Figure 2. Growth of CCRs was fairly slow until 1973 with the onset of the SEER program. During the 1980s, growth in the number of registries has risen sharply. In 1980, there were fewer than 25 CCRs; by 1988, there were 35 statewide programs; and by 1992, there were 39.

Figure 3 shows a comparison of the first year of operations with the first year that population-based data were available. For some of the oldest registries, this interval was quite long, but more recently, registries have population-based data available shortly after they begin their program.



**Figure 3: Comparison of First Year of Operation with First Year Population-based**

Caseload also varies widely among U.S. registries. Figure 4 shows the distribution, sorted from the largest to the smallest, with SEER registries displayed in a different pattern for comparison. California has the largest registry, with more cases than the entire SEER program combined (about 95,700). Most of the SEER

registries range between 10,000 and 20,000 cases, with no individual SEER registry larger than this. The caseload of state registries are more varied: about half of them are larger than 20,000 cases and about 25 percent have more than 40,000 cases reported annually.

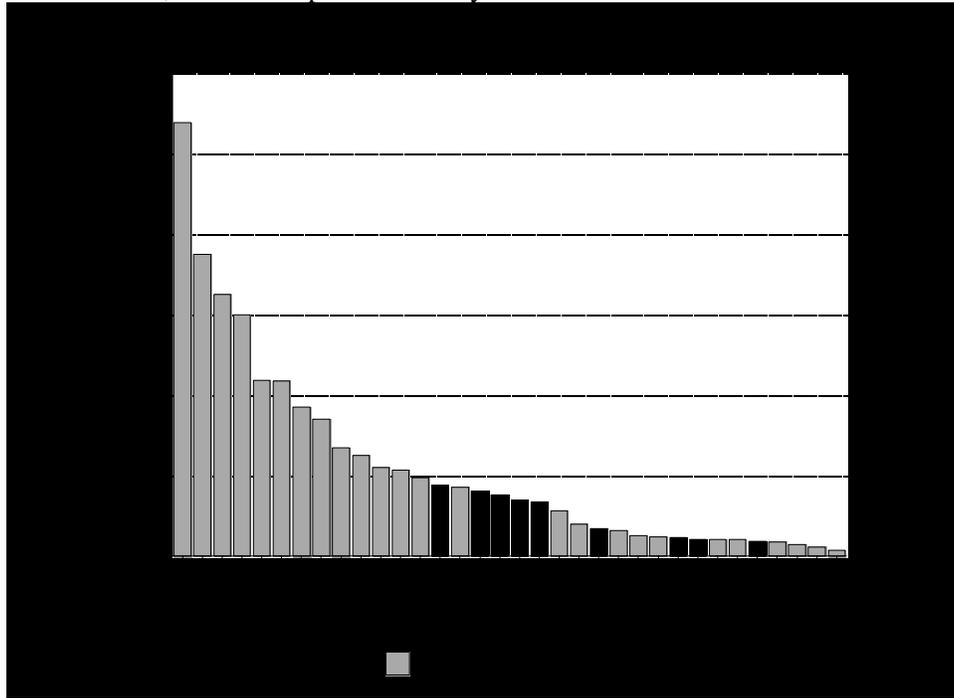


Figure 4: Caseload for SEER and State Registries

### Comparison of Data Quality Indicators

One important component of registry operations is the matching of multiple reports for a single individual. This can be done by computer, manually, or not at all. Most registries, regardless of SEER status, match first by using a computer match program and then resolve potential matches through a manual review process, as shown in Figure 5.

	TOTAL		SEER		STATE	
	N	%	N	%	N	%
Manual	4	13	1	11	3	13
Computer	4	13	1	11	3	13
Both	24	75	7	78	17	74
Unknown	2	-	0	-	2	-
<b>Total</b>	<b>34</b>	<b>100</b>	<b>9</b>	<b>100</b>	<b>25</b>	<b>100</b>

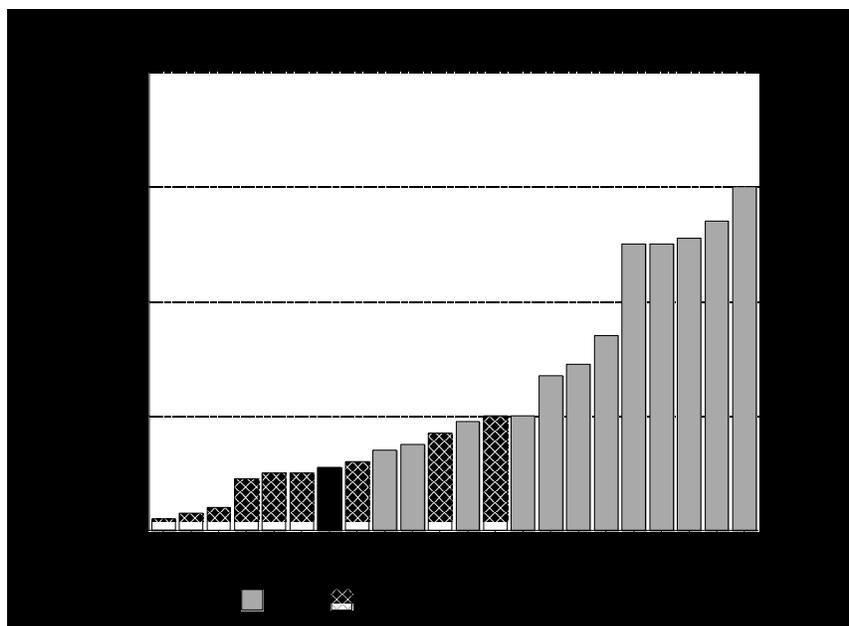
Figure 5: Resolution of Duplicate Case Reports by SEER and State Registries, 1988-1989

	SEER		SEER		SEER	
	N	%	N	%	N	%
< 90	3	11	0	-	3	17
90 - 94.9	10	37	4	44	6	33
95+	14	52	5	56	9	50
Unknown	7	-	0	-	7	-
Total	34	100	9	100	25	100

Histologic confirmation of the tumor is another important indicator of the quality of reported data. As summarized in Figure 6, there is little difference between SEER and state programs with regard to the proportion of cases with at least 95 percent histologic confirmation. However, all SEER programs attain at least 90 percent confirmation, while some state programs fall below 90 percent.

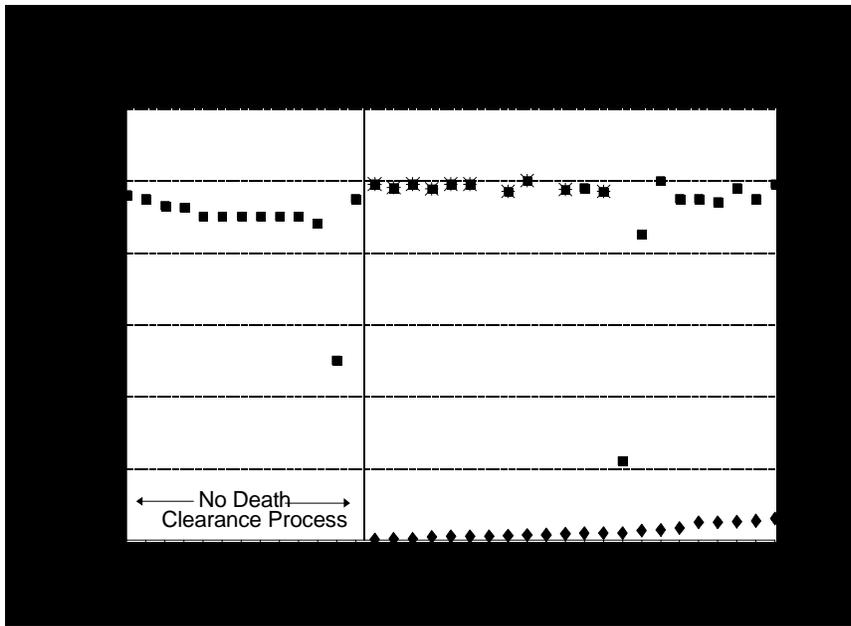
**Figure 6: Percent of Cases with Histologic Confirmation by SEER and State Registries, 1988-1989**

Another measure of quality is the percent of death certificate only (DCO) reports on the registry. These are persons who die with a diagnosis of cancer on the death certificate, but for whom no incident report exists on the database. The proportions of DCOs by state are shown in Figure 7. Many registries, however, did not have a death clearance process in 1988 and did not add deaths to their registry. These states, not shown in the graph, are Illinois, Rhode Island, Pennsylvania, Maine, Missouri, Indiana, Massachusetts, Florida, Montana, Tennessee, North Carolina, and New Hampshire.



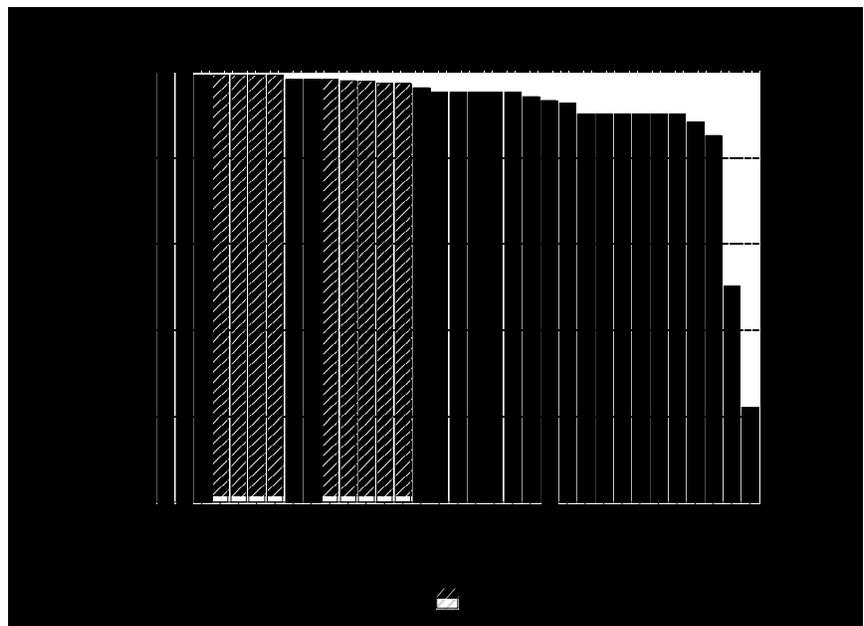
**Figure 7: Percent of DCOs, SEER and State Registries, 1988-89**

The proportion of DCOs can be related to two factors, not directly reflective of poor quality. One, young registries may have artificially high DCOs, because the cases were diagnosed before the onset of the registry program, and therefore do not match with an incident report. And two, some states elect not to deal with DCOs until the registry is more mature and a substantial percentage of the deaths would be expected to match with an incident report. It is reasonable to begin a DCO clearance activity by the time a registry is between 5 and 10 years old.



**Figure 8: Comparison of Self-reported Completeness with Proportion of DCO Reports**

Figure 8 compares the self-reported completeness of case ascertainment with the proportion of DCOs. It is evident that the DCO clearance procedure is associated with more complete case ascertainment, with few exceptions. The SEER registries cluster at the low end of the DCO spectrum, reflecting either a very effective death clearance program or very few missed cases. The states without DCO data shown on the graph are those that do not conduct death clearance procedures.



**Figure 9: Self-reported Completeness of Case Ascertainment, 1988-1989**

Figure 9 shows the sorted ranking of the self-reported completeness of case ascertainment for all registries, with the SEER registries in a different pattern for comparison. All registries aim for 100 percent completeness, but achieving 95 percent is considered to be very good.

**Comparison of Casefinding Sources among U.S. Registries**

Although most cancer patients are hospitalized at some point during their care, the hospital as a casefinding source alone will not identify all cancer cases within a population. Cutaneous melanoma and non-invasive cervical cancer are examples of cases that can be missed because they can be managed outside the hospital setting. Pathology laboratories can be an important source for case finding. Pathology labs are used for casefinding by all SEER registries, however less than half of state registries use this source (see Figure 10).

Another casefinding source is CCRs in other states, as state boundaries are not barriers to patients seeking cancer care. Inter-state data exchanges between central registries are an important source for casefinding. Within the continental U.S., Maine is the only state that shares only one border with another state. Florida, South Carolina, Washington, and Delaware share only two borders with other states. It is relatively common for states to share borders with five or more states.

As an example, outside the metropolitan Chicago area, Illinois is very rural. Illinois shares borders with five other states. In the southern portion of the state, there are no major roads that run east-west. For residents of these areas, medical care is often more convenient and more accessible in a city of a neighboring state. These patterns of care have a strong impact on the complete-ness of case ascertain-ment, and consequently, calculation of incidence rates for border counties and counties in the southern half of the state.

Illinois has 102 counties. Figure 11 shows the distribution of county cancer incidence rates for males, both before and after data are added from the out-of-state CCRs. Several things are notable: the rates shift higher with fewer counties exhibiting rates below 300 cases per 100,000; there is less variation in the rates across all counties; and with the out-of-state data, most of the counties cluster within a few categories, all of which reflect reasonable age-adjusted rates for cancer incidence (using the 1970 U.S. standard population).

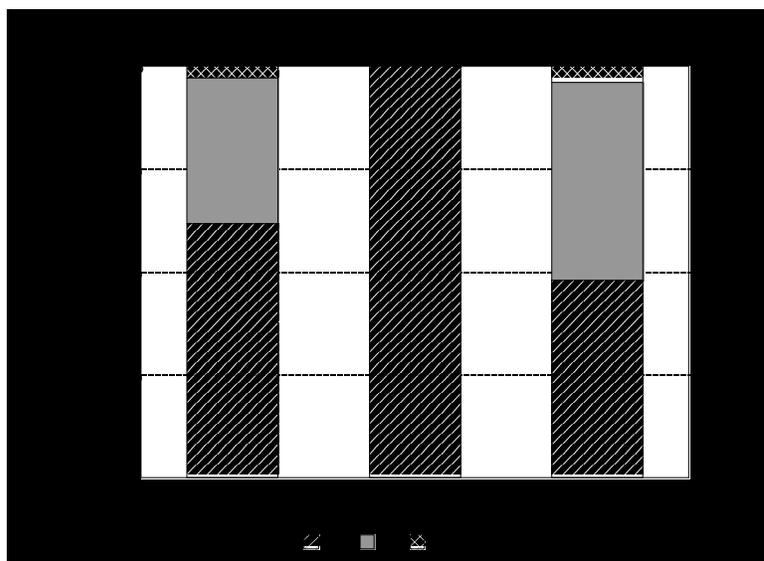


Figure 10: Percent using Pathology Labs for Case Ascertainment by SEER and State Registries, 1988-1989

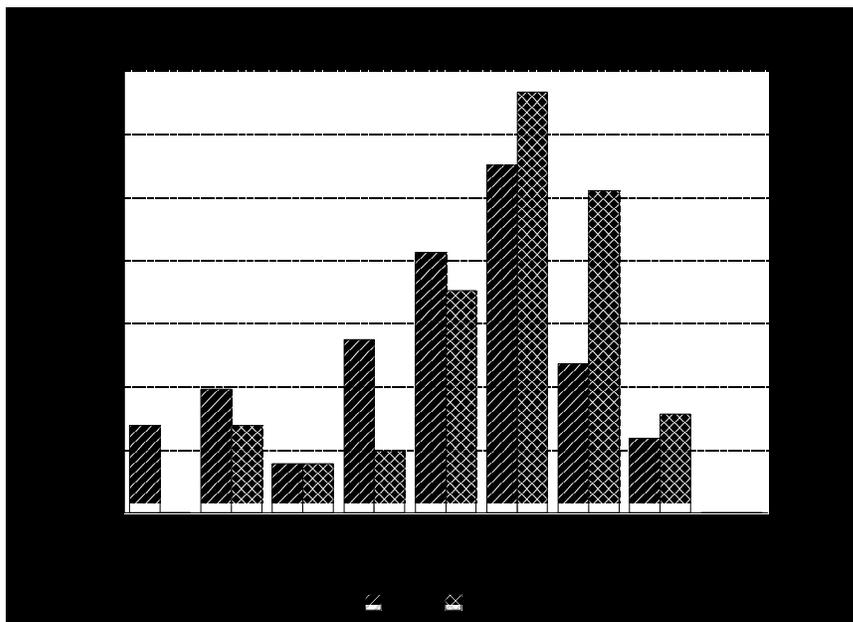


Figure 11: Percent Distribution of County Rates per 100,000 population by Data Exchange, Males, Illinois, 1986-1990

Future reports will include descriptive analyses of registry data from more recent AACCR publications, including cancer registries in Canada.

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