

Overview

What Is the Wisconsin Cancer Reporting System (WCRS)?

The Wisconsin Cancer Reporting System (WCRS) collects and processes information on cancer cases in Wisconsin. In addition, WCRS provides data and produces reports on cancer incidence and mortality statewide and other geographic areas in Wisconsin, by gender, anatomic site (e.g. *breast, lung, colon, and prostate*) and stage of disease.

One of the oldest cancer registries in the country, WCRS has been collecting information on Wisconsin residents with cancer for over 40 years. The first state mandate requiring hospitals and physicians to report cancer cases was passed in 1976 by the Wisconsin State Legislature. WCRS began collecting data from Southeast Wisconsin that year. In 1978, WCRS began collecting data statewide.

In 1995, WCRS began receiving funding from the Centers for Disease Control and Prevention (CDC) through a cooperative agreement under the *Cancer Registries Amendment Act*. These funds have permitted WCRS to make improvements in the collection and processing of data, such as increasing the number and quality of data elements collected on each cancer patient, consistent with standards of the National Program of Cancer Registries (NPCR). Also through this agreement, WCRS began applying national standard edits to cancer cases. Since 1995, WCRS data have been available on public use query sites, provided to researchers, and submitted annually to CDC and standard setters.

Why Report to WCRS?

WCRS is a population-based cancer registry responsible for collection of demographic, diagnostic, and treatment information on patients with active cancer disease that was diagnosed or treated at hospitals, laboratories and physicians throughout Wisconsin.

In determining case reportability, WCRS follows rules of the Surveillance, Epidemiology and End Results (SEER) Program of the National Cancer Institute (NCI). Data items are based on fields required or recommended by the National Program of Cancer Registries (NPCR) for central registries. Additional fields are required for quality assurance.

WCRS collects a variety of information that can be used for research, public health planning, and evaluation. Because the data are population-based, it can be used to monitor incidence patterns in the state.

Data items collected by WCRS are used to:

- ✓ Determine cancer rates and trends
- ✓ Prepare health policy and planning
- ✓ Conduct research in epidemiological studies (including case-control studies)
- ✓ Evaluate cancer control interventions
- ✓ Identify and target high-risk populations
- ✓ Respond to public concerns regarding perceived excesses of cancer

WCRS plays an important role in research to identify causes of cancer. Researchers have used the data to identify cancer patients who could be interviewed about possible exposures they had before being diagnosed with cancer. These responses can then be compared to interview responses of people without cancer to determine whether there were different exposures. One study found a possible association between alcohol intake and breast cancer. Researchers can use WCRS data to determine whether groups of people with specific exposures (e.g. those who work in a particular occupation) are more likely to develop cancer than people who do not have these exposures.

IMPORTANT: Submission of data is mandated under Wisconsin Statute, Chapter 255.04.

Who Reports to WCRS?

All Wisconsin hospitals, laboratories and physicians in certain settings must report information concerning any person diagnosed as having cancer or a precancerous condition to WCRS.

Physicians licensed in Wisconsin working in any of the following settings:

- ✓ Radiation Treatment Centers
- ✓ Ambulatory Surgery Centers
- ✓ Nursing Homes
- ✓ Hospice Centers
- ✓ Clinics
- ✓ Private physician offices
- ✓ Diagnostic and Treatment Centers

By law, Wisconsin facilities and physicians are required to report active primary cancers to WCRS; specific reporting requirements are described in *Chapter 1*. A facility may be small or large, and the extent of information submitted varies depending on facility size, services available to the patient, and reporting methods for each facility. Some facilities have their own cancer registries, in accordance with the American College of Surgeons Commission on Cancer (ACoS - CoC) requirements, while others have limited registries or no registry and only provide the minimum data required by Wisconsin law.

Wisconsin cancer reporting requirements are governed by chapter 255.04, Wisconsin Statutes; Wisconsin Administrative Rule DHS 124.05(3)(h); NPCR requirements as defined under Public Law 102-515; NPCR program standards and NAACCR reporting standards. Copies of the statute, administrative rule and Public Law 102-515 are included in *Appendix II*.

Data Exchange Agreements

To ensure cancer reporting is as complete as possible, WCRS established formal agreements with 45 states and 2 U.S. territories, including all neighboring states except Minnesota, to exchange information regarding cancer patients. The lack of reporting from the Minnesota state cancer registry is concerning for WCRS since many Wisconsin residents are diagnosed and treated in that state. To reduce the effect of underreporting for citizens living in Western Wisconsin, WCRS has individual data agreements with many Minnesota hospitals to collect data on Wisconsin residents seen over the border for their cancer diagnosis and/or care. There are still major gaps in reporting. For example, *Mayo Clinic* in Rochester, Minnesota diagnoses or treats approximately 1,200 Wisconsinites annually but does not share their data with WCRS. However, the data would be much less complete without the voluntary reports we get from some Minnesota hospitals. Their willingness to contribute to Wisconsin cancer control and prevention is highly appreciated.

What Information Is Collected About Patients with Cancer?

In 1976, when WCRS started collecting data, only a minimal amount of information about the patient and tumor was collected. Over the years, as the population ages and knowledge about the disease increases, along with continued research, the volume of cancer cases has increased and the amount of data collected for each case has expanded. Data can be divided into two major types: information pertaining to the disease process and information about the patient.

Disease-process data includes:

- ✓ Anatomic site of the tumor, such as *breast*, *lung*, or *lymph nodes*.
- ✓ Stage of disease at the time of diagnosis
- ✓ Cancer cell type, such as *leukemia*, *melanoma*, and *osteosarcoma*.
- ✓ Type of first course treatment rendered to destroy the tumor

Example: surgery chemotherapy, or immunotherapy.

If a person is diagnosed with more than one type of cancer in his/her lifetime, the same information is collected for each new unique tumor.

WCRS also collects specific socio-demographic information on each person diagnosed with cancer consisting of, but not limited to:

- ✓ Sex
- ✓ Age at time of diagnosis
- ✓ Race
- ✓ Residence at time of diagnosis
- ✓ Longest held occupation
- ✓ Place of birth
- ✓ Ethnicity (Hispanic or non-Hispanic)

IMPORTANT: In 2004, WCRS began collecting data on brain and nervous system tumors classified as benign or which have an uncertain behavior. While these benign tumors won't metastasize beyond the tissue they originated, they are treated aggressively as if they were malignant, which is one of the main reasons those cases are reported.

In total, more than 160 different data items are collected for each person in the WCRS database. The database contains data on all malignant cancers, except *basal* and *squamous cell* skin cancers and non-invasive (*in situ*) *cervical* cancers. Malignant cancers include those with invasive and *in situ* behavior. *In situ* cancers are early cancers that have not extended into the organ to which they are attached or have not spread to other parts of the body. Invasive cancers have invaded into the organ of origin or spread beyond that organ.

How Are Cancer Reports Submitted to WCRS and Processed?

Electronic cancer reporting is required in Wisconsin. WCRS uses a secure internet application called *Web Plus* developed by the CDC for most data submissions. A separate Department of Public Health (DPH) Hypertext Transfer Protocol Secure (HTTPS) and CDC-developed public health information network messaging system are used for *Early Case Capture* pediatric reporting and submissions from out of state pathology laboratories. WCRS supports a data entry software application called *Abstract Plus*, which is used for abstracting and creating files that are submitted using *Web Plus*. *Abstract Plus* contains all required data items, edits for state-mandated reporting, and has built-in online help features, reference manuals, and pre-populated pull-down menus for many data items.

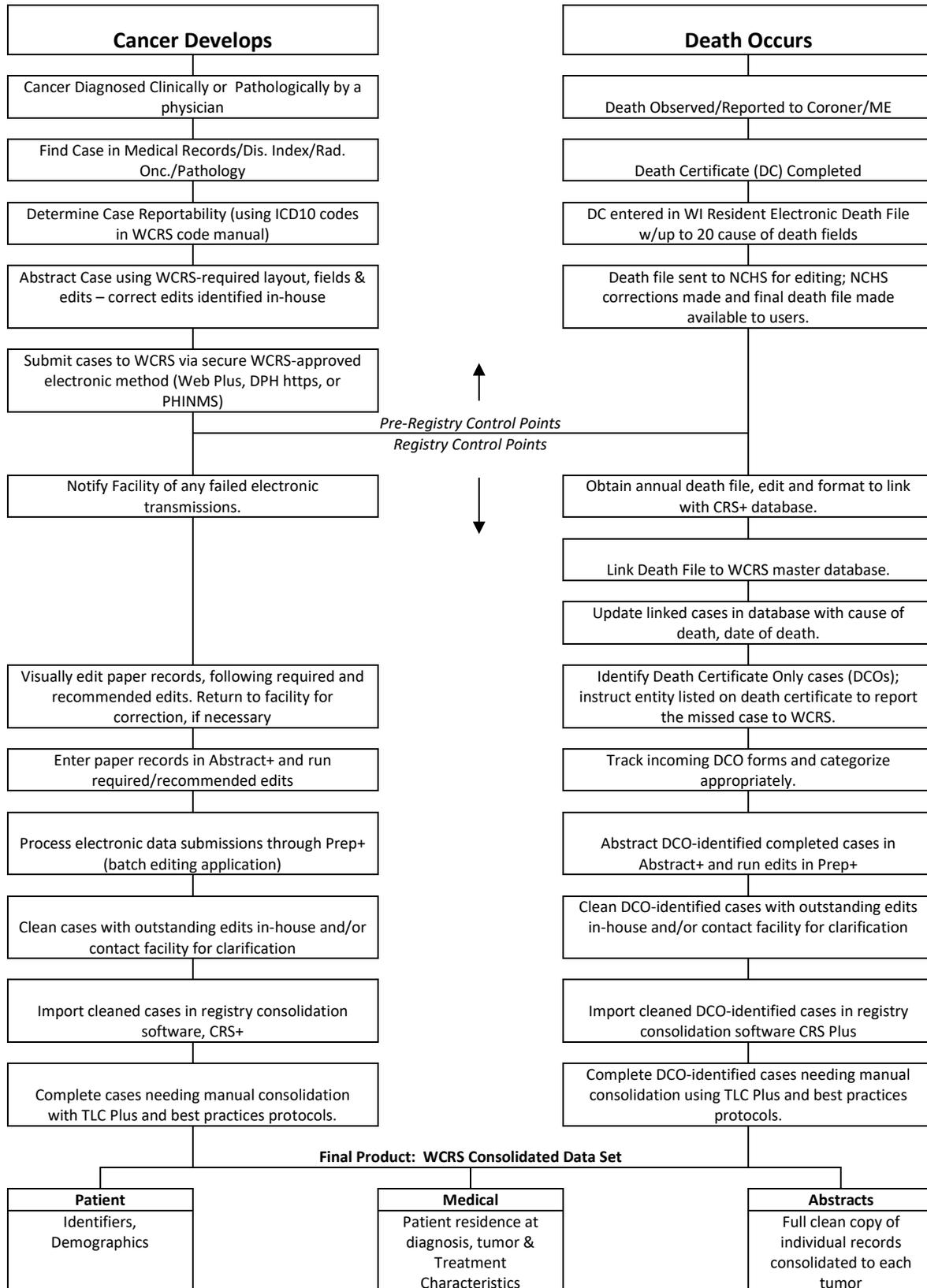
Note: Facilities should electronically submit cancer case files via *Web Plus* at least once a month for annual caseloads over 500, or quarterly for smaller annual caseloads.

Once WCRS receives the uploaded files, they are processed through a series of computerized and manual operations before the files can be used for analysis. In addition, WCRS uses CDC software to visually edit a percentage of random sample cases.

One of the primary strengths of WCRS data is *multiple-source* reporting to ensure statewide coverage and completeness because patients are often seen at more than one facility for diagnosis, treatment, or follow up. On average, 1.6 reports are received for each primary tumor diagnosed. Incoming reports are electronically matched with patients already in the WCRS database. If the incoming record does not match, it is added as a new patient and tumor in the database. For patients that do match, a second match is run to determine if the tumor on the incoming record is already in the database, or is a new tumor. Certified Tumor Registrars (CTRs) at WCRS manual conduct this match. About 13.8 percent of patients in the database have multiple primaries, meaning they have more than one cancer in their lifetime. For some types of cancer, such as *melanoma* and *pharyngeal* cancers, the number of multiple primaries for a person may be high.

WCRS monitors the number of cases submitted by each facility and the total number of cases for a given diagnosis year. Although facilities are required to submit cases within six months (12 months for breast cancer cases), some cases are not received until after a year or more has passed. This affects the completeness and quality of data WCRS includes in publications and online query systems. In recent years, WCRS has been working to improve timeliness and completeness of facility reporting through biannual *Feedback Summary Reports* and working with the American Cancer Society to acknowledge timely and complete reporting with the annual *Data Merit Awards*.

Cancer Incidence and Mortality Data Flow 2018



What Is the *Death Certificate Only* Process?

WCRS begins the *Death Certificate Only* process once most of the data for the most recent diagnosis year are received and processed.

When the Wisconsin Vital Records Section receives death certificates, an *underlying cause of death (UCOD)* is assigned based on the causes of death listed. Up to 20 conditions can be factored in the determination of the UCOD, including history of cancer, which can be listed regardless of whether the person died as a direct result of the cancer. For example, if the decedent died from pneumonia but was diagnosed with prostate cancer two years prior, the cancer is listed as a *significant condition* on the death certificate.

Each year WCRS links the death file to the WCRS database to identify persons in the database who have died and adds the date and UCOD to the record. In instances when no person match is found, or when the type of cancer on the death certificate is different from that recorded in the WCRS database, the result is a *Death Certificate Only (DCO)*, meaning the cancer was listed on the death certificate but WCRS does not have a record of that cancer. WCRS is required to follow-back with the hospital, physician, or coroner listed on the death certificate to request information on the cancer diagnosis. If a DCO is proven not to be reportable to WCRS (the patient was actually a resident of another state when diagnosed, for example) the DCO is deleted. When a full abstract is provided for a missed case the case is no longer considered a DCO and the abstract is added to the database as a complete case.

DCO process improves the completeness of data and identifies missing data submissions or facilities that need to improve their casefinding routines. If a facility receives many DCOs it probably means that there was a failed file submission or your casefinding routine is not catching all of the reportable cancers and needs to be updated. WCRS cannot use solely the information on the death certificate because it does not provide the true year of diagnosis, stage of disease, histology, treatment provided, and other information.

There are approximately 600-800 DCO cases each year that WCRS was not able to follow up on to complete or delete. These '*lost to follow up*' DCOs are often hospice or nursing home deaths, or the physician listed on the death certificate is not associated with a Wisconsin hospital and the address on file is no longer valid.

File Retention

There is no statute governing how long reporting facilities must keep cancer case abstracts or files. However, WCRS recommends retaining them for at least seven years. WCRS's *Abstract Plus* data entry software has a backup function that should be routinely used to backup the database on a network drive. You can call WCRS with questions about file backup. If your facility uses a commercial cancer software product, you should contact your software representative or information technology department for instructions.

Are There Measures of Quality Applied to the Cancer Registry?

Three national indicators measure the quality of cancer reporting:

1. Percentage of cases reported by death certificates only (DCO)
2. Percentage of cases confirmed microscopically
3. Percentage of cases with nonspecific diagnoses

The number of DCO cases indicates the completeness of casefinding within a facility. The number of microscopically confirmed cases and the number with nonspecific diagnoses (unknown primary site, subsite or cell type) measure the accuracy of the information provided. A high percent of cases without microscopic confirmation or with nonspecific diagnoses can indicate inadequate medical record abstracting and reporting, or that the diagnostic work-ups were not as complete as they could have been.

WCRS uses the indicators below, along with the national indicators, to also measure data quality and identify areas for improved reporting from facilities:

- ✓ Percent of cases reported with only a PO Box for the street address
- ✓ Cases with an unknown stage at diagnosis
- ✓ Cases with an unknown maiden name
- ✓ Cases with an unknown race

WCRS uses the following measures to calculate timeliness of cases submitted:

- ✓ Percent of cases received within six months
- ✓ Percent of cases received within nine months
- ✓ Percent of cases received within 12 months
- ✓ Percent of cases received after 12 months

WCRS measures the completeness of cases submitted by diagnosis year against the estimated annual caseload for each facility:

- ✓ 100% of annual estimated caseload submitted
- ✓ 95% of annual estimated caseload submitted
- ✓ 90% of annual estimated caseload submitted
- ✓ Less than 90% of annual estimated caseload submitted

WCRS provides biannual *Feedback Summary Reports* to reporting facilities that focuses on timeliness, completeness and select data quality indicators, as mentioned above.

Is It Necessary to Submit Corrections or Changes to Records?

The change/correction procedure ensures that the most accurate information is available to users by enabling reporting facilities to provide updated or corrected information to WCRS after the original case has been transmitted.

A representative from WCRS may need to contact a facility if questionable or inconsistent information was received or when required data fields are missing. In addition to correcting the information in the software being used at the facility, corrected information must be provided to WCRS as soon as possible.

Example 1: At the time a case was reported to WCRS, the primary site was *unknown*. On a subsequent admission several months later, the primary site was documented as upper lobe of the left lung. **Submit an update** to revise the primary site, laterality and any information that may have become available.

Example 2: A case was reported before the radiation treatment was started or completed. **Submit an update** with radiation treatment information.

Example 3: A case was submitted stating the primary site was *cervical lymph node* and the morphology was *adenocarcinoma*. Because a lymph node is a secondary (metastatic) site of an adenocarcinoma, **the facility would be contacted to request further review** of the medical record to determine the actual primary site.

Note: More details on how to submit a change are in *Chapter 3*.

What Are the Differences Between WCRS and Hospital Discharge Files?

Hospitals report many of the same data items on the same patients to different agencies and this can be burdensome. It is important to understand the uses and needs of data collected through cancer reporting statute 255.04 and Chapter 153, which contains the mandate for hospital discharge data collection.

The *Wisconsin Hospital Association* (WHA) maintains a database of all hospital discharges in Wisconsin, including information on treatment, cost, and patterns of care related to cancer. Cancer patients may be admitted to the hospital many times during their treatment and recovery. Often, a patient is seen at several different hospitals over the course of several years.

Note: WCRS counts the number of primary tumors diagnosed in a person's lifetime, not the number of hospital admissions that person had for cancer. Counting tumors is not possible with WHA data because discharge files do not contain clinical information needed to determine whether a cancer is a new tumor or a recurrence. In addition, data elements important for studying cancer—such as *stage at diagnosis*, *histology*, *behavior* and *laterality*—are not available in discharge files.

How Does WCRS Protect Privacy?

Per Wisconsin Statute 255.04(3), “Any information reported to the department under sub. (1) or (5) which could identify any individual who is the subject of the report or the person submitting the report shall be confidential and may not be disclosed by the department.” See *Appendix II* for more information on state statute and federal law protecting confidentiality.

WCRS policy identifies the following required data items as confidential:

- ✓ Patient name
- ✓ Street address
- ✓ Date of birth
- ✓ Social security number
- ✓ Patient medical record number
- ✓ Cancer registry patient accession number (assigned by facility)
- ✓ Name of physician
- ✓ Date of death
- ✓ Death certificate number

WCRS policy identifies the following combinations of data items as potentially identifying, based on the combined number of items and the geographic size of the area being analyzed:

- ✓ Age
- ✓ Race
- ✓ Sex
- ✓ Year of diagnosis
- ✓ Cancer site
- ✓ Cancer cell type
- ✓ Geographic area

Policies and procedures are in place to protect patient’s privacy. Access to WCRS work areas is restricted and WCRS employees sign confidentiality agreements and conduct annual training on handling confidential information. Statute and policies govern the release of data to outside investigators. All research studies involving data with patient identifiers must comply with Wisconsin Statute, Chapter 255.04(3)(c),(8),(9) and (10) and be approved by the Division of Public Health’s Data Governance Board. Individual-level data without identifiers for small geographic areas are also protected by data release policies. Statistics for areas smaller than the county level are only released when there are enough cases in the area to guard against revealing confidential information about an individual. When there are fewer than six cases of a particular type of cancer in small area the exact number of cases is not revealed.

The *Health Insurance Portability and Accountability Act* (HIPAA) allows reporting of identifiable cancer data to public health entities. Because WCRS is a public health authority, HIPAA allows your facility to report cancer incidence data in compliance with Wisconsin Statute 255.04 and Administrative Rule DHS 124.05(3) (h). Written informed consent from each cancer patient reported to public health entities is not required under HIPAA, nor is a Business Associate Agreement required; rather, facilities must document that reporting has occurred.

What Kind of Data Does WCRS Release?

De-identified data are submitted annually to NAACCR for registry certification and publication in *Cancer in North America*. Registries whose data meet established criteria for timeliness, accuracy and completeness are recognized as NAACCR-Certified registries. WCRS is recognized as a NAACCR *Gold-Certified Registry*. WCRS submits data to CDC for inclusion in the *United States Cancer Surveillance* annual publication and is recognized as a *Registry of Excellence*. CDC provides de-identified Wisconsin data to national and international organizations for use in public use data query systems and publications.

WCRS data are available on the Division of Public Health's *Wisconsin Interactive Statistics on Health* (WISH) website at <https://www.dhs.wisconsin.gov/wish/cancer/index.htm> and the Cancer-Rates.info site, <http://www.cancer-rates.info/wi/index.php>. Data can be filtered by cancer incidence, mortality, stage of disease at the time of diagnosis, and geographic location.

Periodically, WCRS produces *exclusive reports* and *collaborative reports* that include more detailed data than are available online. These are on the WCRS website at <https://www.dhs.wisconsin.gov/wcrs/data-pubs.htm>. Examples of exclusive reports include "Changing Incidence in Lung Cancer Among Women in Wisconsin: Emerging Trends from the WCRS" and "The Increasing Burden of Liver Cancer in Wisconsin." The "Wisconsin Facts and Figures" (WCRS and the *American Cancer Society Midwest Division* collaborative report) is our most frequently visited report.

WCRS releases confidential data to qualified researchers when all statutory requirements have been met and the *Data Governance Board* has approved the request. More details on how to apply are available at: <https://www.dhs.wisconsin.gov/wcrs/researcherinfo.htm>.

Wisconsin Is in the SEER Program! What Does That Mean?

On May 1, 2018, Wisconsin was one of 19 jurisdictions (states, metropolitan regions and tribal nations) awarded a National Cancer Institute *Surveillance and Epidemiology End Results* (SEER) contract, with a 10-year period of performance, May 1, 2018 through April 30, 2028.

Wisconsin is currently awarded for just one of the three main components covered in the contract.

Which Component Did SEER Award WCRS?

1. ***Core Infrastructure Support Activities***

This component includes all activities surrounding core registry operations and functions of a SEER central cancer registry: collection and submission of population-based cancer data including incidence, treatment, and survival following SEER reporting requirements. ***WCRS was not awarded funds for this major component.***

2. ***Virtual Pooled Registry***

This component includes registry participation to support a *one-stop shopping* process through which interested researchers can submit one research application and one research file which will undergo standardized linkage simultaneously at multiple registries. ***WCRS was not awarded funds for this component.***

3. ***Programmatic Meeting***

This component required participation in the initial *programmatic kick-off meeting* for all newly contracted SEER jurisdictions. It satisfies the requirement of being awarded this contract, and allows WCRS to apply for funds to support the core infrastructure and the virtual pooled registry components over the next 10-year contract period. ***WCRS was awarded funds to participate in the meeting.***

What Does This Mean for Cancer Reporters?

- There are no changes to Wisconsin's current reporting requirements as posted on the WCRS web site.
- WCRS is not submitting data to SEER for its Calls for Data or other research projects or patterns of care studies.
- WCRS is not receiving funds from SEER for any core registry activities, staff, or software maintenance.

WCRS is working with SEER and other partners to attain *core registry* status. That will require many transitions including adding data items to the required reporting list, participating in SEER *Calls for Data* and other studies, and converting the current CDC *Registry Plus* software to the *SEER Data Management System*.

Until then, WCRS will continue to use CDC *Registry Plus* software and maintain current reporting requirements as assigned through CDC's NPCR, along with current state-specific reporting requirements.

What Does This Mean for Researchers?

- There is no change to research application requirements as specified in the WCRS *Research Application Manual* posted on the WCRS web site.
- The long-term SEER award does not change data availability listed in the manual's *data inventory* and *data dictionary*.
- Future opportunities in research are expected to be available after WCRS advances in the SEER *core registry* program.