



WISCONSIN CANCER REPORTING SYSTEM AGGREGATE DATA REQUESTS



Policy for Release of Aggregate Data

DESCRIPTION: This policy applies to the release of aggregate data from the Wisconsin Cancer Registry (WCRS). Computerized information for each case of cancer occurring in Wisconsin is captured from medical records of patients who have cancer and reported to WCRS by health care facilities. By law, all active primary cancer cases diagnosed or treated in Wisconsin must be reported to the WCRS.

Cancer cases of Wisconsin residents that were diagnosed in certain other states are also obtained for inclusion to the WCRS database. Wisconsin does not have a state wide exchange agreement with the Minnesota state cancer registry, and therefore cancer cases from counties located on the Minnesota border, and Wisconsin residents diagnosed in Minnesota facilities are not always represented in the database.

GENERAL ACCESSIBILITY: Release of aggregate data will not include access to identifying information (e.g., name and address). All identifying data captured from the medical record is considered confidential and release of aggregate data will be formatted to ensure the confidentiality of all reported cancer cases. Persons may request these data by completing the WCRS Aggregate Data Request stating: (1) the uses for which the information is desired, (2) preferred breakdown of cases (e.g., primary site, sex, race, etc.), and (3) assurances that the data will be released, published or otherwise disseminated in accordance with the data release policies outlined by the WCRS. If requested data are available in published reports or public use data, the requestor will be directed to available data sources. Cancer data are available for cases diagnosed in 1995 through the most recent year for which data are considered complete and approved for release.

INACCESSIBLE DATA: Aggregate data are suppressed when fewer than six (6) incidence cases are reported for any given subgroup over any given time period. Rates are suppressed when calculated on fewer than six (6) incidence cases. Data are suppressed when fewer than ten (10) mortality cases and rates are suppressed when calculated on fewer than ten (10) mortality cases. These suppression rules apply regardless of time frame or for any time period. Suppression is necessary to prevent the potential identification of individuals diagnosed with cancer. Other data may be suppressed if potentially identifiable cases are requested or complimentary and multiple variables increase the likelihood of individual identities being revealed.

CHARGE POLICY: Access to aggregate data may be provided at no charge if data are generally available from existing statistical programs and current databases. If data require preparation for special retrieval or analysis, a charge may be applied.

PROVISION OF DATA: All data will be supplied in tabular format unless otherwise requested, subject to approval. The data will contain all cancer cases accessible for the period of time specified by the request. WCRS accepts late cases for all years and case consolidation may result in different counts for future data requests.

AGGREGATE DATA REQUEST
WISCONSIN CANCER REPORTING SYSTEM (WCRS)

Wisconsin Cancer Reporting System (WCRS)
1 West Wilson, Room 118
Madison, WI 53703

Name of Person Making Request	Title
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Name of Organization

Street Address	City / State / Zip Code
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Phone Number	Fax Number	Requestor's Email Address
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Purpose for which data are requested (please be specific and use additional sheets if needed)

Project / Grant / Title

Reason / purpose of data request

Description of data requested

Is there a deadline for receipt of data? <input type="checkbox"/> Yes <input type="checkbox"/> No	If Yes, please provide date and reason :
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Preferred data table format <input type="checkbox"/> Excel spreadsheet <input type="checkbox"/> SEER*Stat table <input type="checkbox"/> Other, specify: _____

1. Specify cancer site(s)

2. Which cancer data? <input type="checkbox"/> Incidence <input type="checkbox"/> Mortality	3. Case Counts? <input type="checkbox"/> Yes <input type="checkbox"/> No
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4. Statistics requested Frequencies: Age-adjusted rates (standard): Crude rates: Age-specific rates: If yes, which age groups? Confidence intervals: Other, specify:

5. Time frame (year of diagnosis – year of death) _____ thru _____

6. Sex of cases / deaths <input type="checkbox"/> Females <input type="checkbox"/> Males <input type="checkbox"/> Both

7. Race <input type="checkbox"/> All races <input type="checkbox"/> White <input type="checkbox"/> Black <input type="checkbox"/> Other – Specify: _____	Ethnicity <input type="checkbox"/> Hispanic <input type="checkbox"/> Non-Hispanic
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8. Geographic region / breakdown (county, region, state) - Specify selections

9. Other requested variables

10. Other comments of instructions

The Wisconsin Cancer Reporting System will be acknowledged using the suggested references in any publications and/or presentations based on the data provided. Source: Wisconsin Cancer Reporting System, Office of Health Informatics, Division of Public Health, Department of Health Services.

WCRS AGGREGATE DATA USE AGREEMENT

1. I will not allow others to, nor will I myself, match this data set to other patient-level data sets, health care facility and/or professional level characteristics or use these data to identify any health care facility, health care professional or patient without prior Wisconsin Cancer Reporting System approval.
2. The Wisconsin Cancer Reporting System does not warrant the accuracy of any information in the records that will be provided and shall not be held liable for any inaccuracies in such records or any damages from the use thereof.
3. I understand that a copy of the final analysis or research findings generated using these data should be provided to the Wisconsin Cancer Reporting System before publication.

SIGNATURE – Requestor

Date Signed

Please return completed form to:

Attn: Angela Whirry-Achten, Population Registries Unit Supervisor
Wisconsin Cancer Reporting System
1 W. Wilson St., Rm. 118
Madison, WI 53703
Fax: 608-266-2431
Email: angela.whirryachten1@dhs.wisconsin.gov