

## Cancer-Related Databases: Survey of Essential Fields--Explanations

Database/System and Contact Information	Race & Ethnicity	IRB Approval Required	Reports	Comments
<p>Maryland Cancer Registry (MCR)</p> <p><a href="http://fha.maryland.gov/cancer/mcr_home.cfm">http://fha.maryland.gov/cancer/mcr_home.cfm</a></p> <p>Center for Cancer Surveillance and Control, Family Health Administration, DHMH</p> <p>410-767-4055</p>	<p><u>Race</u> 30 categories, as of diagnosis date 2010: 01) White; 02) Black; 03) American Indian, Aleutian, or Eskimo (includes all indigenous populations of the Western hemisphere); 04) Chinese; 05) Japanese; 06) Filipino; 07) Hawaiian; 08) Korean; 09) Asian Indian (code retired for V12); 10) Vietnamese; 11) Laotian; 12) Hmong; 13) Kampuchean (Cambodian); 14) Thai; 15) Asian Indian or Pakistani, NOS (code 09 prior to Version 12); 16) Asian Indian; 17) Pakistani; 20) Micronesian, NOS; 21) Chamorro; 22) Guamanian, NOS; 25) Polynesian, NOS; 26) Tahitian; 27) Samoan; 28) Tongan; 30) Melanesian, NOS; 31) Fiji Islander; 32) New Guinean; 96) Other Asian, including Asian, NOS and Oriental, NOS; 97) Pacific Islander, NOS; 98) Other; 99) Unknown</p> <p><u>Multirace</u> Yes, multirace data collected. There are five (5) race fields per person, each able to capture the 30 categories of race. Registrars are instructed to code known race in Race 1 and "88" in the remaining 4 race fields if multiple race is not designated in the medical chart.</p> <p><u>Ethnicity</u> The MCR has always collected Hispanic ethnicity; however, the variable was not always reported by reporting facilities or the data were not in the medical chart. There is a field to capture birth country, but facilities do not routinely report the information. The MCR currently uses the NAACCR algorithm to derive Hispanic ethnicity based on last and maiden names when ethnicity is non-Hispanic or missing.</p>	<p>IRB approval is required when there are less than 6 patients in one output data cell or when patient name or other identifying information is needed for information or research.</p> <p>See Data Use Policy at: <a href="http://fha.maryland.gov/cancer/mcr_data.cfm">http://fha.maryland.gov/cancer/mcr_data.cfm</a></p>	<p>Incidence and Mortality Annual Reports; Cancer Incidence Summary; Cancer Mortality Summary</p> <p>Cigarette Restitution Fund Cancer Reports are available at: <a href="http://fha.maryland.gov/cancer/surv_data-reports.cfm">http://fha.maryland.gov/cancer/surv_data-reports.cfm</a></p>	<p>The data fields that can be used for statewide analysis are limited. Data from hospitals that utilize certified tumor registrars are of better quality than data from other facility types. The quality of older treatment data is unknown. The MCR database has been geocoded from 2001 to the present and has Zip code, census tract, block group, latitude and longitude.</p>
<p>Maryland Behavioral Risk Factor Surveillance System (BRFSS)</p> <p><a href="http://www.marylandbrfss.org">www.marylandbrfss.org</a> <a href="http://www.cdc.gov/brfss">www.cdc.gov/brfss</a></p> <p>Office of Health Policy and Planning, Family Health Administration, DHMH</p> <p>410-767-5159</p>	<p><u>Race</u> FIVE CATEGORIES: 1) White; 2) Black or African American; 3) Asian; 4) Native Hawaiian or Other Pacific Islander; and 5) American Indian or Alaska Native.</p> <p>THREE CATEGORIES: 1) White; 2) Black or African American; and 3) Other. The Other category is a grouping of Asian, Native Hawaiian or Other Pacific Islander, and American Indian or Alaska Native.</p> <p><u>Multirace</u> Yes, collect as a separate variable. Same 5 categories are used. Began collecting multirace in 2001.</p> <p><u>Ethnicity</u> Yes, respondents asked whether they are Hispanic or Latino.</p>	<p>Not applicable. The source BRFSS database is not released. BRFSS staff have a signed agreement with the IRB not to release any confidential source or derived variables. Another reason for not releasing line-listed data is the technical complexity of the way the BRFSS relational database is structured and standardization of definitions used for analysis and reporting.</p>	<p>BRFSS Summary Report (See Maryland BRFSS Web site); ad hoc reports can be extracted at the Maryland BRFSS Web site or at the CDC site, selecting state as "Maryland." Data at the Maryland BRFSS site tends to be more recent.</p> <p><a href="http://www.marylandbrfss.org">www.marylandbrfss.org</a> or <a href="http://www.cdc.gov/brfss">www.cdc.gov/brfss</a></p>	<p>Zip code has been collected since 2005, but is not yet available from the BRFSS website.</p> <p>For reasons involving technical complexity, the BRFSS database is not released, even with IRB approval.</p>

Database/System and Contact Information	Race & Ethnicity	IRB Approval Required	Reports	Comments
<p>Maryland Cancer Survey (MCS)</p> <p><a href="http://fha.maryland.gov/cancer/surv_home.cfm">http://fha.maryland.gov/cancer/surv_home.cfm</a></p> <p>Cigarette Restitution Fund Program, Center for Cancer Surveillance and Control, Family Health Administration, DHMH</p> <p>410-767-0791</p>	<p><u>Race</u> 5 Categories, plus Other: 1) White; 2) Black or African American; 3) Asian; 4) Native Hawaiian or Other Pacific Islander; 5) American Indian or Alaska Native; 6) Other (specify)</p> <p><u>Multirace</u> Yes. Respondents can select 'all that apply' from the 5 race categories. Multirace data are collected as part of the race question, not as a separate item.</p> <p><u>Ethnicity</u> Yes, respondents are asked whether they are Hispanic or Latino.</p>	<p>IRB approval is required for release of datasets that include county, age, and race.</p> <p>There is a public use dataset that can be released without IRB approval. This dataset has race in three categories (White, Black/African American, and Other), age in multiyear categories, and area of residence in two categories (urban and rural).</p>	<p>Statewide MCS reports are available for 2002, 2004, 2006, and 2008 (age 40 and over). One-time surveys include Physician Survey (2004); Montgomery County Latino Survey (2005); and Baltimore City Cancer Survey (2007).</p> <p>Survey reports are available at: <a href="http://www.fha.state.md.us/cancer/surveillance/html/data_reports.cfm">http://www.fha.state.md.us/cancer/surveillance/html/data_reports.cfm</a></p> <p>User-generated surveys are available on Maryland BRFSS website (state-level data only).</p>	<p>The statewide MCS does not capture persons younger than 40 years of age, non-English speaking residents, and residents without land-line telephones. Data are self-reported, and respondents may refuse to answer any survey question(s).</p>
<p>Maryland Vital Statistics Administration (VSA)</p> <p><a href="http://vsa.maryland.gov">http://vsa.maryland.gov</a></p> <p>Maryland Vital Statistics Administration, DHMH</p> <p>410-764-3038</p>	<p><u>Race</u> 10 Categories: 1) White; 2) Black; 3) Native American; 4) Chinese; 5) Japanese; 6) Hawaiian; 7) Filipino; 8) Other Asian or Pacific Islander; 9) Not Classified; 10) Everything else</p> <p><u>Multirace</u> Not yet available. Plans are to begin reporting in 2010 data when the new birth system is operational.</p> <p><u>Ethnicity</u> Yes, Hispanic origin</p>	<p>IRB approval is required if an individual in the database can be identified. The researcher must provide justification for the requested data.</p> <p>Requests for data requiring IRB approval are made to:</p> <p>Isabelle Horon, Dr.P.H., Director, Vital Statistics Administration, 4201 Patterson Ave., 5th Floor, Baltimore, MD 21215</p>	<p>MD Vital Statistics Annual Reports are available at: <a href="http://vsa.state.md.us">http://vsa.state.md.us</a></p>	<p>Data about country of origin is collected, but only a limited number of country codes are used. Individual countries can be identified only for: Canada, Mexico, Puerto Rica (a territory), and the United States.</p> <p>Persons born in other countries who died in Maryland can be identified only by major world region (Central or South America, Western Hemisphere, etc.)</p>

Database/System and Contact Information	Race & Ethnicity	IRB Approval Required	Reports	Comments
<p>Maryland Medical Care Database (MCDB)</p> <p><a href="http://mhcc.maryland.gov/health_care_expenditures/mcdb.html">http://mhcc.maryland.gov/health_care_expenditures/mcdb.html</a></p> <p>Center for Information Services &amp; Analysis, Maryland Health Care Commission</p> <p>410-764-3570</p>	<p><u>Race</u> Race data are not collected.</p> <p><u>Multirace</u> Not applicable</p> <p><u>Ethnicity</u> Ethnicity data are not collected</p>	<p>To obtain the privately insured data, the requestor must enter into a contract with MHCC and the contract is subject to assessment by MHCC's Institutional Review Board (IRB). MHCC is prohibited from providing access to the Medicare data.</p> <p>IRB approval is required for line-listed data containing sensitive data elements: Patient Identifier, Patient Zip Code, Practitioner Zip Code, Procedure Codes, Diagnosis Code, Patient Covered by Other Insurance, Coverage Type &amp; Delivery System, and Practitioner Specialty Designation.</p>	<p>Report categories in PDF format include: Annual Reports on Maryland Health Care Expenditures, Professional Services Utilization, Insurance Coverage, and special studies by MHCC.</p> <p>Numerous reports are available on the MHCC website: <a href="http://mhcc.maryland.gov">http://mhcc.maryland.gov</a></p>	<p>The Maryland Medical Care Database is comprised of three primary files: 1) the Medical Services file (Encounter Component), the Prescription Drug file (Pharmacy Component), and 3) the Medicare file. Data for the first two files are collected from Maryland insurance companies and exclusive provider organizations (EPOs), called "payers." They contain data about outpatient services. The Medicare file (Medicare Component) contains outpatient claims data involving traditional Medicare beneficiaries.</p>
<p>Maryland Hospital Discharge Database</p> <p><a href="http://www.hsrc.state.md.us">www.hsrc.state.md.us</a></p> <p>Maryland Health Services Cost Review Commission (HSCRC)</p> <p>410-764-2605</p>	<p><u>Race</u> 7 categories:</p> <p>1) White; 2) African American; 3) Asian or Pacific Islander; 4) American Indian/Eskimo/Aleutian; 5) Other; 6) Bi-Racial; and 7) Unknown</p> <p>Note: Items #3 &amp; #4 are non-typical groupings.</p> <p>Note: Bi-Racial occurs for about 2 discharges per 1000.</p> <p><u>Multirace</u> Not collected; bi-racial data are collected</p> <p><u>Ethnicity</u> Yes, Spanish or Hispanic origin (yes, no, or unknown).</p>	<p>IRB review is required when the data analyst or researcher is asking for medical record-type variables, which, in combination, could identify a patient (e.g., date of admission, age, Zip code, etc.)</p> <p>For details about IRB procedures see: <a href="http://mhcc.maryland.gov/irb">http://mhcc.maryland.gov/irb</a></p>	<p>Policy reports are posted to the HSCRC Web site. Types of information reported include: case mix, patient acuity, financial reporting, diagnostic related group (DRG).</p> <p>Reports on cancer-related hospital discharges, by year of discharge, can be found on the following website: <a href="http://fha.maryland.gov/cancer/surv_data-reports.cfm">http://fha.maryland.gov/cancer/surv_data-reports.cfm</a></p>	<p>The non-confidential dataset can not be geocoded because it does not include address of patient.</p> <p>HSCRC also has a confidential dataset.</p>