

2021 NPCR MARYLAND SUCCESS STORY

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Data Release Documentation for Researchers

National Program of Cancer Registries SUCCESS STORY

SUMMARY

The Maryland Cancer Registry (MCR) developed a data release coversheet as a clear way of describing the data that researchers will receive.

CHALLENGE

Researchers requesting registry data did not always understand what was included and excluded in their requested data sets. The specifications of each released data set provided to researchers were also not documented.

SOLUTION

MCR staff developed a data release coversheet to reassure researchers of the integrity of the MCR disclosure. The data release coversheet is used for line listed data, which is often based on a data request of all the cases of a certain gender, race, time frame, primary site, stage, and/or location.

The data request coversheet includes multiple sections. The first section describes the study and includes the name of the principal investigator, the name of the study, and a request number (generated by the MCR). The second section describes the actual data released, the date of release and whether the request was for a data linkage or a confidential line list. The next section lists all the variables included in the data set provided in response to the researcher's request. Data requests with many variables are provided with a study data dictionary. In such cases, the other fields line is often filled out with the statement "Refer to the study data dictionary."

On the coversheet, the "Source of the Data" notes the data set used, which is named after the date extracted. For linkages, the data source is the most recent cut to contain the most matches. Data cuts occur at least quarterly. For line listed requests, static data are used. Since the data set changes continuously, as new cases are reported and consolidated, the MCR cuts a static data set once per year for the MCR's official numbers. This allows the MCR to answer questions about the official figures and to replicate those numbers at any time in the future.

The last two sections of the data release coversheet describe the inclusion or exclusion of data from other sources, such as data from other states or death data. The MCR adheres to certain terms and conditions that may prohibit or limit the re-release of data from certain sources. For example, the number of cases from interstate data exchange and the states are noted. If data are solely received from interstate data exchange, data are not released. However, if there are many cases from another state, the researcher can contact that state and request that they allow the MCR to release that data. Data received from the Veteran's Administration are not released and data received solely from the Maryland Vital Statistics Administration are not released without a sign off on the Institutional Review Board (IRB) request from the Vital Statistics Department. If a sign off has been received from the Vital Statistics Administration, then all requested variables, death date, cause of death, and vital status can be released. Only date of death and vital status can be released if the death information was received from the National Death Index (NDI).

RESULTS

As a result of the data release coversheet, MCR staff have answered fewer questions by researchers. Researchers commented that the instructions were clearer and easier to follow. If there are questions or a need for additional variables, the MCR staff knows which data to use and what has been released.

SUSTAINING SUCCESS

The data release coversheet improved communications with researchers, and the MCR will revise the coversheet as changes are made in the registry community.

REGISTRY CONTACT INFORMATION

410-767-5459

https://health.maryland.gov/phpa/cancer/pages/mcr_home.aspx



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