

**Delaware Cancer Registry Data Access for Research
Data Request Process**

<p>Guidelines for use of Delaware Cancer Registry (DCR) data in research activities and publications</p>	<p>The National Program of Cancer Registries of the Centers for Disease Control and Prevention provides funding and technical support to the Delaware Cancer Registry under a cooperative agreement. When data from the Delaware Cancer Registry are used for research and publication, the NPCR must be acknowledged in the text, using a statement similar to the following: <i>“These data were collected by the Delaware Cancer Registry and other central cancer registries participating in the National Program of Cancer Registries (NPCR) of the Centers for Disease Control and Prevention (CDC).”</i></p>
<p>How to Submit</p>	<p>All requests for Delaware Cancer Registry (DCR) data must be reviewed by the Delaware Division of Public Health (DPH) Privacy Board. As detailed below, a completed application and required documentation must be submitted.</p>
<p>Process</p>	<p>The researcher will submit the data request package to the DPH Privacy Board. The type of form the researcher will need to submit will depend on the type of data to be requested.</p> <ol style="list-style-type: none"> 1. The researcher will start by going to the data information and request page here and answering the question(s) starting with ‘Do you need a public use data file?’ Dependent upon the answers to the questions, the site will direct the researcher to the appropriate form that they will need to complete and submit. There are three types of data requests: <ul style="list-style-type: none"> • Public Use Data: aggregated or record level data that has been stripped of the 18 identifiers specified by HIPPA and therefore is not considered Protected Health Information (PHI). • Limited data: data that do not contain personal identifiers, but do contain individual specific data such as city, zip code, census tract, elements of dates relegated to a person, and other unique characteristics. • Protected data: data that includes confidential, personal identifiers such as name, Social Security Number, and full address. Requests for Protected data will require additional time for review and approval by the Human Subjects Review Board. 2. The DPH Privacy Board will notify the researcher of their decision on fulfillment or if there are any questions regarding the request in writing within five business days. 3. If approved, the DPH Privacy Board will notify the DCR of the request and the DCR will prepare the extracts and data files in accordance with the approved request as resources permit. <p>Note: There are no separate cancer registry forms or applications required for submission by the researcher. It is most beneficial to include all details of the data request in the original data request form, including (but not limited to) population/cancers of interest, variables of interest, and format of data.</p>
<p>Pediatric Research Considerations</p>	<p>Applications for approval of access to pediatric cancer data are the same.</p>
<p>Sponsorship from Local Researcher Required</p>	<p>No</p>

Fees	Currently, there are no fees associated with a request for or access to cancer registry data, including research approval or re-approval.
Timeframe	The approval process will be handled as expeditiously as resources permit, and does not begin until all required forms and supporting documentation are received by the DPH Privacy Board. Review of complex requests may take up to six months. Requestors will be notified of the outcome of the review in writing.
Contact for questions regarding Cancer Registry requests PRIOR to Submitting Requests can be directed to:	<p>Sumitha Nagarajan Chronic Disease Epidemiologist (CDE) Delaware Division of Public Health 302-744-1031 (voice) 302-739-2545 (fax) Sumitha.Nagarajan@delaware.gov</p>