

## Cancer Registry Data Access for Research Data Request Process

<b>Initial Cancer Registry Contact Required Prior to Submitting Application</b>	<p>Dayna Aydin  Manager, Delaware Cancer Registry  256 Chapman Rd  Oxford Building, Suite 100  Newark, Delaware 19702  Phone: 302.283.7203  Fax: 302.283.7201</p> <p><u>and</u></p> <p>Sangeeta Gupta  Chronic Disease Epidemiologist  Delaware Division of Public Health  Email: <a href="mailto:Sangeeta.gupta@state.de.us">Sangeeta.gupta@state.de.us</a>  Phone: 302.744.1036  Fax: 302.739.2544</p>
<b>Type of Contact</b>	Email <u>and</u> Fax
<b>Required Documentation</b>	<ol style="list-style-type: none"> <li>The researcher must submit the following: <ul style="list-style-type: none"> <li>Brief summary of the study including rationale, description of the study, data needed and description of human subjects if applicable, are submitted to the Chronic Disease Epidemiologist and the Delaware Cancer Registry (DCR) Manager.</li> </ul> </li> <li>In addition, if the request is for limited or protected data, the researcher will be asked to complete and submit the appropriate forms and agreements listed below : <ul style="list-style-type: none"> <li>Application for Protected Health Data or Application for Limited Record Data</li> <li>Signed Data Users Agreement</li> <li>Institutional Review Board (IRB) approval from the researcher’s affiliated institution should be included for studies involving follow-back. IRB approval is recommended for but not necessary for studies not involving follow-back.</li> <li>Forms for approval from Delaware Human Subjects Review Board (HSRB), if required.</li> </ul> </li> </ol> <p>Note: There are no separate Cancer Registry forms or applications that are required for submission by the researcher.</p>
<b>How to Submit</b>	The completed application and required documentation will be submitted to the Division of Public Health (DPH) Privacy Board by the Chronic Disease Epidemiologist (CDE).
<b>Process</b>	<ol style="list-style-type: none"> <li>The researcher submits a brief summary of the study including rationale, description of the study and data needed to: 1) Sangeeta Gupta, Chronic Disease Epidemiologist, via email at <a href="mailto:Sangeeta.gupta@state.de.us">Sangeeta.gupta@state.de.us</a> and by fax at 302.739.2544 and 2) Dayna Aydin, DCR Manager by fax at 302.283.2701.</li> <li>The CDE will review the submission package and if needed ask for clarification/additional documentation.</li> </ol>

	<ul style="list-style-type: none"> <li>• If the request involves de-identified or non-protected data, it may be approved without going through a formal application process.</li> <li>• If limited or protected data is requested, a formal application package including application form and Data Users Agreement will need to be submitted to the DPH Privacy Board. The required forms will be provided to the researcher by the CDE. For studies involving follow-back, IRB approval from researcher’s affiliated institution must be included. It is recommended that survey forms to be used in follow-back must also be included.</li> <li>• For studies conducting follow-back, the request will also need to be approved by HSRB. Details of the process will be communicated to the researcher.</li> </ul> <ol style="list-style-type: none"> <li>3. The completed application and required documentation will be submitted to the DPH Privacy Board by the CDE.</li> <li>4. The DPH Privacy Board will notify the researcher of their decision. The CDE will be copied on any communication with the researcher.</li> <li>5. The Chronic Disease Epidemiologist will inform DCR of approved research proposal.</li> <li>6. DCR will prepare the extracts and data files in accordance with the approved request as resources permit.</li> </ol>
<b>Pediatric Research Considerations</b>	Applications for approval of access to pediatric cancer data are the same.
<b>Patient Contact and Consent Procedures</b>	Patient consent is required for research involving patient follow up. The HSRB will have to approve the procedures for a researcher to obtain patient consent.
<b>Sponsorship from Local Researcher Required</b>	No
<b>Fees</b>	Currently, there are no fees associated with a request for or access to cancer registry data, including research approval or re-approval.
<b>Timeframe</b>	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 DCR. Review of complex requests may take up to six months. Requestors will be notified of the outcome of the review in writing.
<b>Special Notes</b>	<ul style="list-style-type: none"> <li>• The state of Delaware recently revised its legislation to include sharing cancer registry data with external sources (researchers outside of the state of Delaware). [Title 16, Chapter 12, Subchapter III, <a href="#">Delaware Code</a>] Previously, cancer registry data was only shared with internal sources within Delaware limits, all of which had patient consent prior to submitting a request</li> <li>• The DCR is in the process of changing procedures for access to cancer data. These new procedures (as outlined above) are currently under review and will be effective upon approval and supersede all previous procedures.</li> </ul>