

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

Initial Cancer Registry Contact Required Prior to Submitting Application	Heather Brown Cancer Program Director (CPD) Delaware Division of Public Health 302-744-1061 (voice) 302-739-2545 (fax) Heather.Brown@state.de.us
Type of Contact	email, phone or fax
How to Submit	The completed application and required documentation will be submitted to the Division of Public Health (DPH) Privacy Board by the CPD.
Process	<p>The researcher submits a brief summary of the study including rationale, description of the study objectives and methodology and data needed to:</p> <p>1) Heather Brown, Cancer Program Director, via email at Heather.Brown@state.de.us or by fax at 302-739-2545</p> <ol style="list-style-type: none"> 1. The CPD will review the submission package and if needed ask for clarification/additional documentation. <ul style="list-style-type: none"> • If the request involves de-identified or non-protected data, the study may be approved without going through a formal application process. • If limited or protected data are requested, the following must be completed by the researcher: <ul style="list-style-type: none"> ○ Application for Protected Health Data ○ Investigator Agreement for the Delaware Human Subject Review Board (HSRB), ○ Application for the Delaware HSRB All Required forms will be provided to the researcher by the CPD. • The following must be included for studies involving follow-back: <ul style="list-style-type: none"> ○ IRB approval from the researcher’s affiliated institution ○ Survey forms to be used in follow-back • Request for studies conducting follow-back will also need to be approved by HSRB. Details of the process are available at http://dhss.delaware.gov/dhss/dms/epqc/hsrbprocedures.html 2. The completed application and required documentation will be submitted to CPD 3. The CPD will submit the package to the DPH Privacy Board. 4. The DPH Privacy Board will notify the researcher of their decision in writing. 5. The CPD will be copied on any communication with the researcher. 6. The Delaware Cancer Registry 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.</p>
Pediatric Research Considerations	Applications for approval of access to pediatric cancer data are the same.
Patient Contact	Patient consent is required for research involving patient follow-back. The HSRB

and Consent Procedures	will have to approve the procedures for a researcher to obtain patient consent.
Sponsorship from Local Researcher Required	No
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 CPD. Review of complex requests may take up to six months. Requestors will be notified of the outcome of the review in writing.
Special Notes	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, Delaware Code] Previously, cancer registry data were only shared with internal sources within Delaware limits, all of which had patient consent prior to submitting a request.