Delaware Cancer Registry Data Access for Research
Data Request Process

Initial Cancer Registry Contact Required Prior to Submitting Application	Heather Brown Chronic Disease Bureau Chief (CDBC) Delaware Division of Public Health 302-744-1020 (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 CDBC.
Process	The researcher submits a brief summary using the attached form of the study including rationale, description of the study objectives and methodology and data needed to: Heather Brown, Chronic Disease Bureau Chief (CDBC), via email at Heather.Brown@state.de.us 1. The CDBC will review the submission package and if needed ask for clarification/additional documentation. • 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: o Application for Protected Health Data o Investigator Agreement for the Delaware Human Subject Review Board (HSRB), o Application for the Delaware HSRB All Required forms will be provided to the researcher by the CDBC. ▪ Details of the HSRB process are available at http://dhss.delaware.gov/dhss/dms/epqc/hsrbprocedures.html 2. The completed application and required documentation will be submitted to CDBC 3. The CDBC 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 CDBC will be copied on any communication with the researcher. 6. The Delaware Cancer Registry (DCR) will prepare the extracts and data files in accordance with the approved request as resources permit. Note: There are no separate Cancer Registry forms or applications required for submission by the researcher.
Pediatric Research Considerations	Applications for approval of access to pediatric cancer data are the same.
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.
Guidelines for use of Delaware Cancer Registry (DCR) data in research activities and publications	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: "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)."