Frequently Asked Questions (FAQ)

Delaware Cancer Registry (DCR) Data Access

1. **What type of information is in the database?**

   The Delaware Cancer Registry (DCR) is a statewide, population-based registry that collects data on all cancer cases diagnosed and/or treated in Delaware since 1980. The DCR contains detailed textual and coded information on diagnosis, demographics, cancer site and type, staging, treatment and vital status for cancer patients diagnosed or treated in Delaware. The DCR adheres to the standards of the North American Association of Central Cancer Registries (NAACCR). For further information on specific data fields that are collected, see this link to the NAACCR Data Dictionary.
   http://www.naaccr.org/StandardsandRegistryOperations/VolumeII.aspx#

2. **What law governs release of the data?**

   Delaware Code - Title 16. Health and Safety, Chapter 12. Informed Consent and Confidentiality, Subchapter III. Confidentiality of Personal Health Information.
   http://delcode.delaware.gov/title16/c012/sc02/index.shtml

3. **How long does the data request process take?**

   The time needed to process a data request depends on the nature of the request. Requests involving aggregate, non-identifiable or non-protected data may be processed in less than four weeks.

   Before the release of data, all research proposals requesting the use of patient-level, limited or protected health information must be reviewed by the Delaware Division of Public Health (DE DPH) Privacy Board and may take up to six months. See the Data Request Process table linked on this site for specific information on the steps in processing of these requests:
   http://dhss.delaware.gov/dph/dcr/files/datarequestprocess.pdf

4. **What is aggregate, non-identifiable data?**

   Data in tabular format that cannot either directly or indirectly identify any patient. To protect the indirect identification of a patient, the DCR uses a rule that any cell containing fewer than 6 cases is suppressed.

5. **What are limited data?**

Limited data are not directly identifiable, but may contain identifiers from the list of 18 identifiers described in the National Center for Health Statistics Staff Manual on Confidentiality such as city, zip code, census tract, and dates related to a person. (http://www.cdc.gov/nchs/data/misc/staffmanual2004.pdf)

6. **What is protected health information (PHI)?**
   PHI is any information, whether oral, written, electronic, visual, pictorial, physical or any other form, that relates to an individual's past, present or future physical or mental health status, condition, treatment, service, products purchased, or provision of care. It also reveals the identity of the individual whose health care is the subject of the information, or about which there is a reasonable basis to believe such information could be utilized) to reveal the identity of that individual. (Delaware Code Title 16, Sec 1230)

7. **What kind of research would be eligible to receive protected health information?**

   Cancer surveillance and control studies using various research methodologies may be eligible. The following criteria must be met:
   - The study is designed to positively impact public health
   - The research methodology meets standards of scientific merit and is feasible and epidemiologically sound, as deemed by the DPH Privacy Board.
   - Researchers provide assurances of protection of confidentiality of data.

8. **Are there other sources of cancer data and statistics that may have the information I am looking for?**

   There are published reports on cancer statistics that are available to the public. See the following links for more information:
   - Delaware Cancer Statistics, Delaware Division of Public Health
     http://dhss.delaware.gov/dph/dpc/ca_stats.html
   - Delaware Cancer Reports, Delaware Division of Public Health
     http://dhss.delaware.gov/dph/pubreportsaz.html#C
   - State Cancer Profiles (National Cancer Institute-NCI)
     http://statecancerprofiles.cancer.gov/
   - Cancer in North America (North American Association of Central Cancer Registries-NAACCR) http://www.naaccr.org/DataandPublications/CINAPubs.aspx
   - Cancer Facts & Figures (American Cancer Society-ACS)
     http://www.cancer.org/research/cancerfactsstatistics/index
   - Cancer Data and Statistics (National Program of Cancer Registries-NPCR)
     http://www.cdc.gov/cancer/npcr/tools.htm