NON-HOSPITAL CANCER REPORTING TRAINING PROGRAM

DELAWARE CANCER REGISTRY

DELAWARE HEALTH AND SOCIAL SERVICES
Division of Public Health

February 2011

CONTENTS

Non-hospital cancer data reporters……..…….. 3
Learning objectives…….…….. 4
General Background……..……... 5
National Program of Cancer Registries……..…….. 7
Goal of data collection……..……... 9
Why non-hospital reporting?..... 10
Types of cancers diagnosed and treated outside the hospital……..…… 11
What happens to cancer data reported to the DCR?..... 13
Confidentiality and legislation…… 14
Why report?..... 17
Delaware Cancer Control Act…… 18
$100 fine for each violation……. 24
How your data is used in the fight against cancer…… 25
Why do all non-hospital facilities need to report?..... 29
Reportable neoplasms…… 33
Using text to select cases to report to DCR…….. 35
Using codes to select cases to report to DCR……..... 38
Exclusions to reporting…….. 40
Timetable for reporting cases to DCR…….. 43
Data submissions – completing the cancer reporting form……. 46

Non-Hospital Data Reporters

- *Physicians*
- *Ambulatory Surgery Centers*
- *Pathology Laboratories*
- *Long Term Care Facilities*
- *Nursing Homes*
- *Hospices*

I. Overall Learning Objectives

This program will help you to:

- **Learn why cancer cases are reported to the Delaware Cancer Registry**
- **Learn which neoplasms are currently reportable to DCR**
- **Understand in which situations to report cases**
- **Learn procedures for reporting cancer case data to DCR**

II. General Background

In this section you will learn about:

- The background and history of the Delaware Cancer Registry
- The importance of cancer data reporting by non-hospital facilities
- What happens to your data after it is reported to DCR
- Issues of confidentiality of data reported to DCR

What is the Delaware Cancer Registry (DCR)?

The DCR is the state's central cancer information center

- Founded in 1972
- Legally established in 1980 through the Delaware Cancer Control Act.

National Program of Cancer Registries (NPCR)

The NPCR provides funding and support for state cancer registries to

- **Monitor cancer trends over time**
- **Determine cancer patterns in various populations**
- **Guide planning and evaluation of cancer control programs**
- **Help set priorities for allocating health resources**
- **Advance cancer research**
- **Provide information for a national database of cancer incidence**

NPCR

- **Delaware was initially funded by NPCR in 1997.**

  See the following website for further information about the NPCR: http://www.cdc.gov/cancer/npcr

- **Like other NPCR state registries, Delaware's central registry is population-based**

  - **identifying and collecting data on *all* cancer patients who are residents of Delaware.**

Goal of DCR Data Collection

The DCR collects information on

- newly diagnosed cancer cases
- cancer treatment
- cancer deaths
  - following cancer patients through their lifetime.

Why Non-Hospital Reporting?

- Shift in recent years toward outpatient diagnosis and treatment for cancer patients
  - In the 1990's approximately **5%** of cancer cases were reported to DCR from non-hospital sources
  - 2008 : approximately **13%** of cancer cases were reported to DCR from non-hospital sources only.

Types of cancers diagnosed and treated outside of the hospital

The most common types of cancer diagnosed or treated outside of the hospital include:

- melanoma
- prostate
- noninvasive bladder tumors
- tumors in colorectal polyps
- lymphoma, leukemia, multiple myeloma and other bone marrow primaries.

Without non-hospital reporting, Delaware cancer statistics would not be accurate…

- ….and the DCR database could not be relied upon to help direct cancer prevention and control efforts

Pathology laboratories, physician's offices, ambulatory surgery centers, long-term care facilities and hospices, together with hospitals, play a key role in the collection of information.

What happens to cancer data reported to DCR?

- A case summary, or abstract, for each cancer case that is reported to DCR is created and added to the DCR database
- Cases already reported by another source to DCR are updated with additional demographic, diagnostic, treatment and follow-up data
- Case information for out of state residents is reported to their respective state cancer registries to assure complete case finding..

Confidentiality of Data is of Crucial Importance to DCR

- The Delaware Cancer Control Act mandates confidentiality of cancer data
- DCR maintains the confidentiality of data
  - Only aggregated data that does not reveal patient identity is released for published reports or to respond to data requests
  - Researchers using confidential data from the registry must obtain approval from Delaware's Human Subjects Review Board.

Legislation and Exchange of Cancer Data

- **the *Delaware Cancer Control Act states that*** "patient-identifying information may be exchanged among cancer control agencies as authorized by the Department …"

- ***HIPAA privacy regulations allow*** the DCR as a public health authority to collect information for the purpose of preventing and controlling cancer**.**

  – "disclosures to public health authorities that are authorized by law to collect or receive information for public health purposes are permissible under the Privacy Rule." (see HIPAA FAQs, DHSS DPH website: www.dhss.delaware.gov/dhss/dph/morefaqshipaa.html)

II. Questions for review

- *In 2005, approximately what percentage of new cancer cases was reported by non-hospital reporters in Delaware?*
- *Name three types of cancer that are more commonly diagnosed and treated outside of the hospital setting.*
- *What is the name of the legislation that established the Delaware Cancer Registry? What year was this legislation established?*
- *Name three categories of non-hospital cancer data reporters*
- *True or False: If an additional report is received on a case which has already been submitted to DCR, the subsequent report is immediately shredded by DCR staff.*

III. Why Report?

Learning Objectives

In this section you will learn about:

- The Delaware Cancer Control Act
- How DCR data is used in cancer surveillance and control efforts

Reporting Legislation: The Delaware Cancer Control Act of 1980

- The purpose of the Delaware Cancer Registry is to insure an accurate and continuing source of data concerning cancer and certain specified benign tumors. The Act can be found at the following site: http://delcode.delaware.gov/title16/c032/index.shtml.

The Cancer Control Act of 1980

- Required that “all hospitals, clinical laboratories, and cancer treatment centers within the state” should report all new cancer cases to the DCR.
- Data is population-based

Amended Act, 1996

- **To assure complete case reporting**, the Delaware Cancer Control Act was amended in 1996 to also require reporting from “any physician, surgeon, dentist, podiatrist or other health care practitioners who diagnoses or provides treatment.”

Follow-up Data is Required per the Cancer Control Act

- Non-hospital offices may be contacted by DCR to obtain additional information such as
  - complete first course of treatment data
  - diagnostic and treatment information for cancer cases identified through death certificate review.

Time Period for Reporting

- The 1996 Amendment specified that cases were to be reported within 90 days of initial diagnosis or treatment

- Current amendment specifies reporting of cancer cases within 180 days of initial diagnosis or treatment, whichever is earlier.

Cancer data required to be reported to DCR

Types of data that are currently collected by DCR include:

- **Cancer Site and cell type**
- **Demographic data**
- **Diagnostic information, including pathology report data**
- **Staging data to assess the extent of the disease**
- **Treatments**
- **Follow-up data, including information on recurrence of cancer and death certificate information**

Fine for Violations

- The Delaware Cancer Control Act specifies a $100 fine for each violation of the Act.
  - One case not reported constitutes a violation of the Act.

How is DCR Data Used in the Fight Against Cancer?

These are examples of how DCR data is used:

- Incidence and Mortality Report issued by DE DPH (see http://www.dhss.delaware.gov/dhss/dph/dpc/ca_stats.html)
  - Annual report
  - Describes trends in cancer rates, by gender, race, county of residence, stage at diagnosis among other factors, and provides comparisons with the U.S. as a whole.

How is DCR Data Used in the Fight Against Cancer?

Report of Disparities in Cancer, DE DPH (see http://www.dhss.delaware.gov/dhss/dph/dpc/ca_stats.html).

- NAACCR's CINA report (http://www.naaccr.org/index.asp?Col_SectionKey=11&Col_ContentID=50)

- NPCR's/National Cancer Institute's publication United States Cancer Statistics (USCS): Incidence and Mortality report is available at http://apps.nccd.cdc.gov/uscs/

How is DCR Data Used in the Fight Against Cancer?

- The Delaware Cancer Consortium and Delaware Division of Public Health use DCR data to help target resources for improvements in screening, prevention and treatments
- Investigations by Delaware Division of Public Health of possible cancer clusters in Delaware
- Treatment and follow-up data collected for use in planned quality of cancer care and survivorship studies

DCR DATA FORMS THE BASIS
FOR CANCER PREVENTION AND CONTROL EFFORTS

III. QUESTIONS for REVIEW

- *Per the Delaware Cancer Control Act, what is the current maximum time interval for reporting cancer cases to DCR, from the time of initial diagnosis or treatment?*
- *True or False: Physicians are required to report only those cancer cases that are diagnosed or treated outside of the hospital.*
- *Name three ways that DCR data is used in the fight against cancer*
- *True or False: The DCR collects data on a cancer patient throughout his or her lifetime.*

IV. Why do physicians, path labs, ambulatory surgery centers and other non-hospital facilities *all* need to report?

Learning Objectives

- In this section, you will learn why reporting from ***all*** non-hospital offices and facilities is essential for complete data collection.

Why all non-hospital facilities in Delaware need to report

- Cancer patients often travel to other states for diagnosis and/or treatment, and DCR might not receive reports from all out-of-state sources

- A patient could be referred to a DE hospital for diagnosis and/or treatment services but ultimately not go there for these services

Why all non-hospital facilities need to report, cont'd

- Data from different reporting sources is consolidated at DCR for a complete, accurate cancer abstract for each case, using reports from various sources.

Even if your center has only minimal clinical data for a particular patient, such as date of diagnosis, cancer site and type, we need you to report this information, as it helps us to create the most complete record possible for the patient.

IV. Questions for review

- *List 3 reasons why **all** Delaware non-hospital facilities need to report cancer data to DCR*

V. What neoplasms are reportable to DCR?

Learning Objectives

In this section, you will learn:

- Which neoplasms are reportable
- Exclusions to reporting

How are cases selected?

Your office may select cases to report to DCR based on:

- text from the patients' pathology report, medical records, or other documentation.
- codes

Please follow these guidelines when selecting cases using *text*:

- **<u>Report</u> neoplasms described with the following terms, FOR ALL CANCER SITES***

- In situ
- Intraepithelial
- Stage 0
- Non-invasive
- Non-infiltrating

*see exclusions page 40

Report neoplasms described with the following terms, FOR ALL CANCER SITES

- cancer
- malignant
- carcinoma
- malignant neoplasm
- adenocarcinoma

Report benign or borderline tumors of the brain and CNS (for diagnoses after January 1, 2004), in any of the following sites:

- Brain
- Meninges
- Other parts of the central nervous system
- Spinal cord
- Craniopharyngeal duct
- Cranial nerves
- Pineal gland

Please follow these guidelines when selecting cases using *codes*:

ICD-9-CM Codes 140.0 – 289.83*

Includes:

- Malignant neoplasms
- Benign brain/CNS neoplasms
- Carcinoma in situ
- Hematopoietic neoplasms

*See *Delaware Cancer Registry Non-hospital Reporting Manual* for additional information on exclusions to reporting

Additional guidelines

- Report each primary site cancer separately. Any concurrent or subsequent diagnosis of or treatment for cancer in another primary site should be reported as a separate case.

Example: A patient has biopsies of the skin on his right and on his left cheek. Pathology results show a malignant melanoma, Clark's level II of his right cheek, and a melanoma in situ of his left cheek. Each case of melanoma should be reported as a separate case.

Exclusions to reporting

<u>Do not report</u>:

- Basal cell and squamous cell carcinoma of skin, except of genitalia. (effective 1/1/2003)
- In situ carcinoma of the cervix uteri
- Cervical intraepithelial neoplasia grade III (CIN III) and
- Prostatic intraepithelial neoplasia grade III (PIN III).

Exclusions to reporting, continued:

- **Do not report** when a patient has *only a history* of cancer with no currently active disease.

V. Questions for review

1. List 3 reportable neoplasms

2. A diagnosis described with the term “noninvasive” should be reported to DCR. (True/False)

2. List skin cancers that ***are*** reportable

VI. When to Report Cases to DCR

- Within 6 months of first contact for diagnosis or treatment, as stated in the Delaware Cancer Control Act

Example: A biopsy is performed at your surgery center on July 1, 2008 – diagnosis - adenocarcinoma of the prostate. This case would need to be reported to the DCR by December 31st, 2008.

Reporting Schedule

- The schedule for reporting cases to the DCR is based on your center's caseload/year

Follow this schedule for reporting cases to the Delaware Cancer Registry

# of Reportable Cases/Year	Reporting Interval
>75	Monthly
25-74	Every other month
<25	Quarterly

VII. DATA SUBMISSIONS

COMPLETING THE CANCER REPORTING FORM

Data submissions must be…

- Timely
- Accurate
- Complete
- Legible

TO AVOID ADDITIONAL FOLLOW-UP CALLS FROM THE DCR!

Cancer Reporting Form (CRF)

- Tool for organizing and collecting cancer data
- Used only for reportable neoplasms
- Separate CRF for ambulatory surgery centers
- Hard copy submissions (US mail, fax)

CRF: General Instructions

1. Please type or print clearly.

2. Complete CRF for *each* cancer diagnosed.

3. Mail/fax completed form along with pathology report and any supporting documentation to:

- Do NOT assume a hospital or other clinician will report.
- No documentation?... Explain why in COMMENTS.

Revised Oct 2007

DELAWARE CANCER REGISTRY

256 Chapman Road
Oxford Building, Suite 100
Newark, DE 19702

Phone: (302) 283-7200
Fax: (302) 283-7201

CRF: Practitioner Identification

Identify the contact data of the diagnosing practitioner/facility

- Practitioner/Facility name
- Practitioner/Facility number
- Phone number
- Postal address
- **Person completing CRF**
- **Date CRF completed**

CRF: Case Identification

Revised Oct 2007

Identify patient personal data and demographics

- **Sex** – gender at birth
- **Race 1,2 –** complete both if multiracial
- **Ethnicity –** Spanish/Latin origin
- **Occupation –** majority of career
- **Company/Industry**
- **Patient address at diagnosis**

CRF: Diagnostic Data

Identify when/where the diagnosis was made,

tumor's anatomical location,

cell/tissue type, size/depth,

and disease stage.

- **Place of Dx** – facility/office where specimen collected
- Attach supporting documentation: path/lab report, AJCC Summary Staging documentation, diagnostic imaging reports

CRF: 1st Course Treatment

Revised Oct 2007

Specify the type ***and*** date of Rx the Pt had.

Specify Pt's vital status, last contact with your facility, disease status, referrals.

- No Rx is a form of Rx.
- Type:
  - Record Surgical procedure(s)
  - Record dosage level
- Provide clinician's name and specialty if Pt was referred to/from your facility.

CRF: Common Data Errors

Error	Solution
▪ Occupation = Retired	⇨ Record patient's usual occupation
▪ Date of Dx = date positive malignancy reported	⇨ Record date specimen was collected
▪ Place of Dx = name of path lab/facility that analyzes specimen	⇨ Record facility/office where specimen was collected

CRF: Common Data Omissions

Omission

- Incomplete practitioner information
- Sex, SSN
- Race, Ethnicity
- Occupation, Place of birth
- Grade, Stage
- Pt status, Date of last contact (if Pt is alive)
- Referrals
- Supporting documentation (path/lab report)

Solution

Report Your Cancer Data!

What *guarantees* a contact from the DCR?

DATA OMISSIONS

DATA ERRORS

NOT REPORTING

ILLEGIBLE HANDWRITING

THANK YOU!!

Together we can assure complete, accurate cancer data for Delaware

We acknowledge the Centers for Disease Control and Prevention for its support of this training program under Cooperative Agreement # U55/CCU321881-05-1