



DELAWARE HEALTH AND SOCIAL SERVICES

Division of Public Health

DELAWARE CANCER REGISTRY®

2009 NPCR Program Directors Conference

DELAWARE CANCER REGISTRY ADVISORY COMMITTEE

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Division of Public Health

The State of Delaware



- **1st state admitted into the Union**
- **2008 Population: 873,092**
(US census estimate)
- **49th state in order of size**

Key Cancer Control Organizations

- **Delaware Cancer Registry (DCR)**
- **Delaware Cancer Registry Advisory Committee (DCRAC)**
- **Delaware Cancer Consortium (DCC)**

Cancer Control Administration in Delaware...

begins with the Governor.

Delaware Cancer Consortium (DCC)

- **Est. March 2001 by Gov. Ruth Ann Minner.**
- **15 member council appointed by the governor.**
- **Task**
 - **To advise the governor and legislature on the causes of cancer incidence and mortality and potential methods for reducing both.**
 - **Create a clear, usable cancer control plan.**

DCC - April 2001

Began developing clear and usable cancer control plan to

- **Create a shared awareness and agreement on the range of cancer control issues to be addressed now and in the future**
- **Create a structure and agenda for addressing these needs**
- **Enable Delaware to move forward with meaningful action for its citizens.**

DCC Cancer Control Plan

First Four-Year Plan, 2002-2006

“Turning commitment into Action”

- Provide colon cancer screening for every Delawarean aged 50+
- Reach the African American population
- Examine Delaware’s waterways/wells for carcinogens
- Offer free cancer Tx to the uninsured
- Inform Delawareans what to do to reduce their cancer risk

DCC Cancer Control Plan

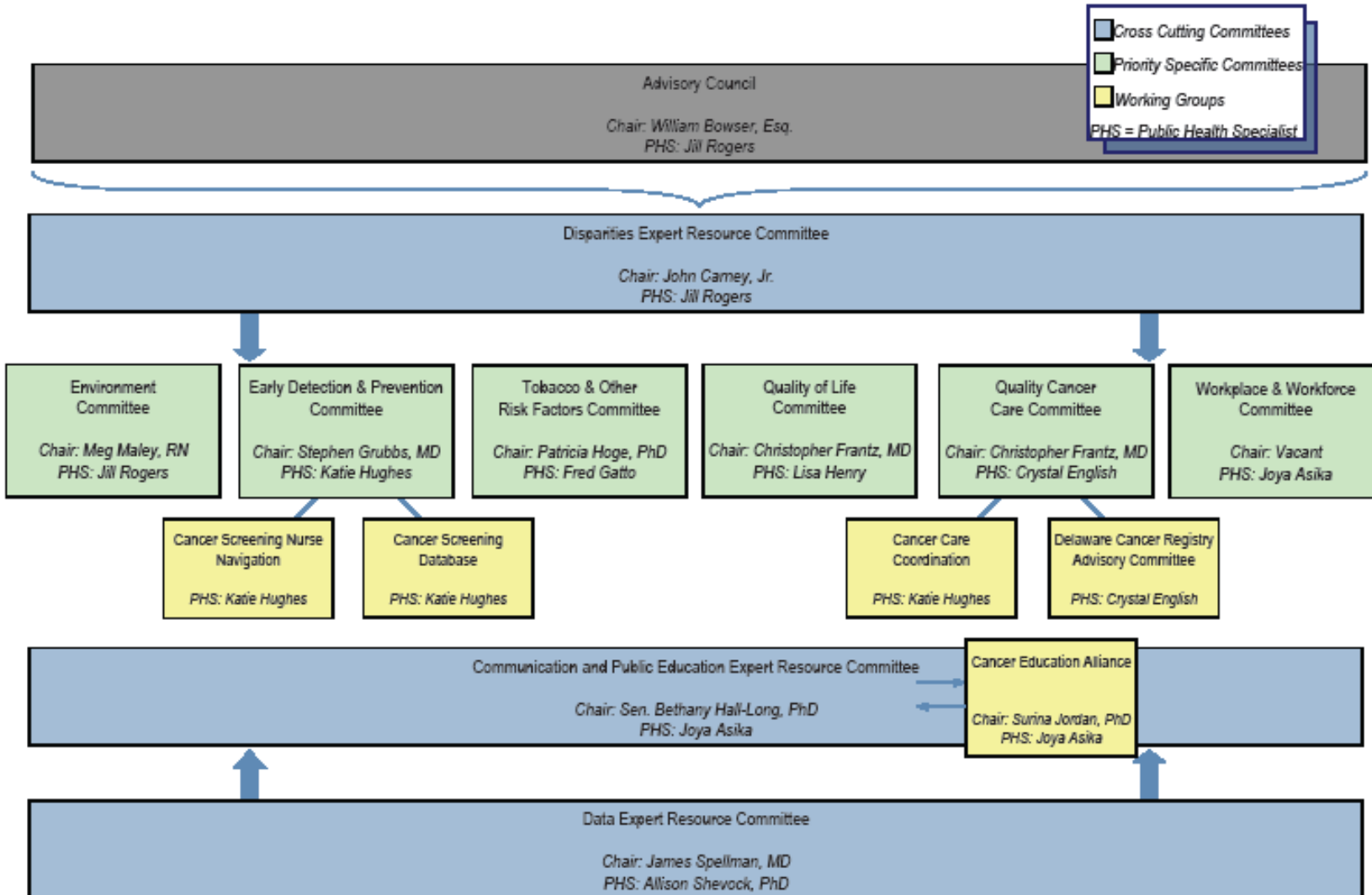
The Next Four-Year Plan, 2007-2011 "Turning action into Results"

- Increase screenings via mobile outreach, partnering with insurance companies
- Reduce prostate, breast, colorectal cancer in the African American population
- Continue monitoring Delaware's waterways/wells for carcinogens
- Extend free cancer Tx to the uninsured from 1 to 2 years

Committees of the DCC

1. **Environment**
2. **Early Detection and Prevention**
3. **Tobacco & Other Risk Factors**
4. **Quality of Life**
5. **Quality of Cancer Care**
6. **Workplace/Workforce**
7. **Disparities**
8. **Communication and Public Education**
9. **Data**

Meet every
other month
for 1.5 hours



What is the Delaware Cancer Registry (DCR)?

The DCR is the state's cancer information center

- **Founded in 1972**
- **Legally established in 1980 through the Delaware Cancer Control Act.**
- **Resides in Dept. of Health and Social Services (DHSS)/Division of Public Health (DPH)**
- **New cancer diagnoses: ~5000/yr**
 - **7 hospital facilities: 88% of cases**
- **5 employees**
 - **2 State**
 - **3 ICF Macro contractors**

What is the Delaware Cancer Registry Advisory Committee (DCRAC)

The DCRAC is a multidisciplinary committee tasked with advising the DCR in the scientific and logistic aspects of

- Cancer data collection**
- Registry operations**
- Policies and program evaluation**
- Best usage of cancer registry data in cancer control initiatives**

to further the cancer control goals of the State.

DCRAC Membership

The members of the DCRAC include

- Oncologists**
- Certified tumor registrars**
- DE DHSS representatives**
- Healthcare planners and policy makers**
- Advocacy organizations.**

DCRAC's History

- **Established in 2005**
- **Meets every other month for 1 hour; meetings coordinated by ICF Macro**
- **Holds periodic strategic planning sessions to develop, prioritize, refocus activities**

DCRAC 2005

Mission and Purpose of the DCR

"The mission of the Delaware Cancer Registry is to help reduce the cancer burden in Delaware, by maintaining a cancer database of excellent quality and completeness, and making this information available to health professionals, researchers, health care organizations and public health professionals for cancer prevention and control efforts.

The purpose of the Delaware Cancer Registry is to collect timely, complete and accurate data from reporting sources to insure an accurate and continuing source of data concerning cancer and certain specified benign tumors. Reporting sources include all health care practitioners who diagnose or treat cancer, as well as hospitals, clinical laboratories, and other cancer diagnosis and treatment facilities within Delaware. The Registry will serve as a source of information to measure quality of cancer care in Delaware."

DCRAC 2005

Initial areas of focus in order of priority

- 1. Timeliness/completeness of data collection**
- 2. Occupancy/residency data collection**
- 3. Procedure for releasing data from the DCR**
- 4. Using DCR data for research**
- 5. Evaluation of DCR's registry software system - electronic data transfer**
- 6. HIPAA regulations impact on DCR's work**

DCRAC 2006-2008

Major strategies developed to address focus areas

1. **Improve timeliness/completeness of data collection- through technological improvements, and by increasing reporting by non-hospital reporting sources such as ambulatory surgery center**
2. **Improve data quality, including staging and treatment data. Improve capture of first course of treatment data, toward the goal of improving treatment for patients with cancers. Enable the routine evaluation of treatment practices and patterns against patient outcomes**
3. **Provide more support to cancer registries/cancer registrars and other reporting facilities in Delaware.**
4. **Increase use of data to answer research questions**
5. **Change Delaware Cancer Control Act to eliminate occupation/residency data collection requirement**
6. **Develop routes of efficient and effective communication between the Registry and its stakeholders, especially healthcare practitioners and facilities, interested agencies and organizations, and the public**
7. **Close gap between timely reports of data**

Strategy 1: Improve timeliness, completeness of data collection

Progress

- Case finding project- free standing ambulatory Sx centers
- Hospital case finding audit
- Increase data collection from non-hospital sources
- Research and write DCR IT needs assessment and recommendations report
- Finalize IT Report and Recommendations
- IT business case presented to DE DHSS
- State approved IT business case

Completed

- June 2006
- October 2006
- December 2006
- March 2007
- January 2008
- June 2008
- October 2008

Strategy 2: Improve data quality, including staging and treatment data – toward the goal of improving treatment of cancer patients

Progress

- Scheduled physician medical record review studies.
- DE hospitals (5) regularly submitting additional 1st course Tx data to DCR.

Completed

- September 2008
- December 2008

Strategy 3: Provide more support to DE cancer registries, cancer registrars and other reporting facilities

Progress

- Developed and facilitated reporter training for non-hospital reporters
- Doubled number of annual training sessions provided to DE registrars in 2008
- Surveyed DE registrars for
 - Training needs/preferences
 - Incentive/recognition award preferences

Completed

- June 2006
- December 2008
- June 2008
- January 2009

Strategy 4: Increase use of data to answer research questions

Progress

- Public use data prepared. State privacy laws prohibit release.
- Data requests to DCR doubled between 2006 and 2008.

Completed

- September 2007
- December 2008

Strategy 5: Amend DE Cancer Control Act to eliminate occupation/residency data requirement

Progress

- Revised Act passed initial review and will go before the Legislature.

Completed

- In progress

Strategy 6: Improve communication between DCR and its stakeholders

Progress

- Established a registry newsletter. Responsibility now transferred to DE Cancer Registrars Association.
- Revised and reissued reporting manuals for both hospital and non-hospital reporters
- Began development of a new DCR webpage

Completed

- April 2007, ongoing
- January 2008
- August 2008

Strategy 7: Close gap between timely reports of data

Progress

- Data request turnaround:
 - 91% filled w/in two (2) days
 - all requests completed w/in nine (9) days.
- Strategy removed

Completed

- September 2007, ongoing
- May 2008

DCRAC Success Factors

Things that have contributed to the DCRAC's success:

- Good mechanics to stay on task**
- Follow up**
- High level support**
- Infrastructure**

Factors Driving Effectiveness

Membership

- participants have perspective on cancer control, not just registry operations

Organizational structure

- DCRAC connected with a wider infrastructure on cancer control
- Works on issues concerning many stakeholders

High level support

Benefits to the DCR

User input

- **Stakeholders bring perspectives beyond registry operations and registry management**

Shift from inward to outward focus

Advocacy

Resources

Delaware Cancer Consortium

<http://www.delawarecancerconsortium.org>

DE Department of Health and Social Services/Division of Public Health

<http://www.dhss.delaware.gov/dhss/dph/index.html>

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**THANK
YOU!!!**

