

DELAWARE CANCER REGISTRY EXECUTION PLAN 2009 – 2011

BACKGROUND

The Delaware Cancer Registry Execution Plan was created in 2006 with the input and guidance of the Delaware Cancer Registry Advisory Committee (DCRAC). The DCRAC was first established in 2005. The DCRAC membership includes oncologists, certified tumor registrars, healthcare planners and policy makers, and representatives of advocacy organizations. Execution Plan tasks from the original 2006-2008 plan were re-prioritized and reworked by DCRAC members for the next three year period of 2009-2011. The revised priorities and accountabilities are shown in the table on the following pages.

The DCRAC provides guidance and support to the Delaware Cancer Registry toward the goal of improving cancer registry operations, including timeliness, completeness and quality of cancer data collection, and on the best use of cancer registry data for cancer surveillance and control initiatives, program planning, and cancer research. In May 2008 a retreat was held to revisit the strategic plan. The committee revised the original plan, and the revisions are incorporated into this document.

MISSION & PURPOSE

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.

DCR PRIORITIES FOR 2009 - 2011 (Action steps are detailed in the accompanying Execution Plan)

1. Improve timeliness/completeness of reporting of cancer case data, through technological improvements and by increasing reporting by non-hospital sources such as ambulatory surgery centers.
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 cancer. Enable the routine evaluation of treatment practices and patterns against patient outcomes.
3. Provide more support to hospital cancer registries/cancer registrars and other reporting facilities such as ambulatory surgery centers
4. Increase use of data to answer research questions.
5. Change Delaware Cancer Control Act to eliminate occupation/residency data collection requirement. Determine feasibility of changing regulations to require reporting of treatment information with follow-up data to DCR.
6. Develop routes of efficient and effective communication between the Registry and its stakeholders, especially with healthcare practitioners and facilities, interested agencies and organizations, and the public. Better, clearer communication of reporting requirements. Improve communication of the benefits of the DCR to the public

DCR Execution Plan 2009 - 2011

Strategy One - Improve timeliness & completeness of reporting of cancer case data, through technological improvements and by increasing reporting by non-hospital sources such as ambulatory surgery centers

Action Step	Priority	Accountability	Progress	Status
<p>Improve DCR's Information Technology capabilities: 1a. Finish IT business case 1b. Meet with IMS</p> <p>Next step: Issue RFP</p> <p>Timeline:</p>	4.3 High	1a. Macro/IT Task Force 1b. DE DPH Issue RFP: DCR	1a. April 2008 - Final draft business case prepared, based on IT Task Force Report and DCRAC review. 1b. IMS staff are on DCRAC's IT Task Force, providing guidance for business case development <ul style="list-style-type: none"> ▪ June - September 2008 - Final business case under review by IMS ▪ October 2008 – Business case approved <p>Assigned task 1/2009: Start RFP development (DCR)</p>	1a. & 1b. DONE
1c. Provide advice, guidance and facilitation for hospitals and registries regarding services available to help with abstracting backlogs. To assist with compliance with legislation and avoidance of \$100 fine.	3.8 Med	DCR & DCRAC		Unmet
1d. Personal contact with physicians, labs and surgicenters, after appropriate specialists/centers have been identified <ul style="list-style-type: none"> ▪ Education of reporters regarding the \$100 fine – through cancer committees, ACOS meeting, DCR training programs <p>Timeline:</p>	3.9 Medium	DCR	<ul style="list-style-type: none"> ▪ Focus groups for IT needs assessment conducted with staff of non-hospital offices ▪ Non-hospital cancer reporting training – Power Point presentation ready to pilot in non-hospital offices ▪ September 2008 – presentation piloted with 5 physician offices in New Castle Co <p>Assigned Tasks 1/2009</p> <ul style="list-style-type: none"> ▪ script a reminder of reporting requirements for cancer committees, Delaware Medical Journal on brain/cns reqs and \$100 fine (Bob McBride) ▪ non-hospital training session scheduled (Betsy Cromartie) 	In progress

Strategy One, continued.....Improve timeliness & completeness of reporting of cancer case data

Action Step	Priority	Accountability	Progress	Status
<p>1e. Explore additional/alternative casefinding and treatment data sources, e.g., provider billing data</p> <ul style="list-style-type: none"> ▪ cross-check DCR treatment data with insurance data (e.g., Medicaid data) <p>Timeline:</p>	<p>3.4 Low</p>	<p>DE DPH/ DCC Data Committee</p>	<ul style="list-style-type: none"> ▪ January 2008- initial meeting with Dr. Spellman, Dr. Shevock, Dr. Kaplan (BCBS) to discuss insurance data merging project. ▪ September 2008 - DPH working with IMS to develop a draft data use agreement between BCBS and DPH. <p>Assigned Task 1/2009: Ask DCC Data Committee for progress report/report back to DCRAC (Judy Walrath)</p>	<p>In progress</p>
<p>1f. Explore use of linkage with DHIN</p> <p>Timeline: On hold until pilot is underway</p>	<p>3.8 Medium</p>	<p>DE DPH – Dr. Silverman</p>	<ul style="list-style-type: none"> ▪ November 2007 – IT Task Force is working with DHIN staff toward long range goal of cancer case reporting to DCR through DHIN ▪ January 2009 - Pilot project planned with DPH & DHIN - focusing on immunization program 	<p>In progress</p>
<p>1g. Evaluate feasibility of hospital-based registries using a partitioned, hospital-specific portion of the central registry in place of their facility-based registries.</p> <p>Timeline: Long term; dependent upon IT development</p>	<p>2.8 Low</p>	<p>DCRAC/DPH</p>	<p>Under consideration by IT Task Force/DCRAC</p>	<p>In progress</p>
<p>How Do We Measure Success?</p> <ul style="list-style-type: none"> ▪ Installation of new IT system <ul style="list-style-type: none"> * NAACCR certification (completeness and timeliness measure) ▪ # of people trained on new system ▪ 			<ul style="list-style-type: none"> ▪ # of users ▪ Increased physician reporting - 2003 – 2006 diagnosis year case reports - reports submitted only by non-hospital sources increased by 200/year 	

Strategy Two - Improve data quality – 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.

Action Step	Priority	Accountability	Progress	Status
<p>2a. Study of % Stage III colon cancer patients who receive adjuvant chemotherapy: source document review, including 3rd party carriers, as part of a permanent task force for cancer care chart review</p> <p>Timeline:</p>	<p>3.9 Med</p>	<p>Dr.s Grubbs, Petrelli, Spellman;</p> <p>DCC Data Committee</p>	<ul style="list-style-type: none"> ▪ 2007: The DCC made a recommendation that a permanent site visit team of physicians convene for regularly scheduled hospital medical record and hospital/State registry review. ▪ April 2008 – contracts in place for colorectal cancer Stage III study; preliminary analyses of central cancer registry data underway ▪ September 2008 - Study sample selected, additional treatment data collected, and preliminary analyses performed <p>Assigned Tasks 1/2009:</p> <ul style="list-style-type: none"> ▪ Discuss with Data Committee possibility of collaborating with DCRAC on next research question; propose using same items ACOS is looking at (Judy Walrath) ▪ Dr. Petrelli will work with Karen Nunley to schedule chart reviews 	<p>In progress</p>
<p>2b. Design a state cancer report card (including data on how state practitioners are doing in regard to diagnosing, staging, and treating cancer patients, e.g % early stage at diagnosis, standard of care) Use EQUIP/QOP data reports as foundation. Report card to be published.</p> <p>Timeline:</p>	<p>3.6 Low</p>	<p>DCC Data Committee</p>	<p>No progress to report</p> <p>Assigned Task 1/2009: Develop template for a report card using ACOS EQUIP report. (Bob McBride) Judy and/or Bob to report back from Data Committee to DCRAC re: progress.</p>	<p>In progress</p>

How Do We Measure Success?

- Collect complete first course of treatment data – As of September 2008, five DE hospitals have submitted additional first course of treatment data to DCR
 - Results of internal audit of data – high quality
 - Continue to achieve NAACCR Gold Standard - **Gold standard achieved in May 2006, May 2007& May 2008**
 - Hospital audits (compare chart to hospital registry)
- *Physician & public feedback

Strategy Three - Provide more support to hospital cancer registries/cancer registrars and other reporting facilities in Delaware.

Action Step	Priority	Accountability	Progress	Status
<p>3a. Support hospital CTRs – i.e., formal training at DCRA meetings</p> <ul style="list-style-type: none"> ▪ Survey CTRS: Evaluate quality/usefulness of trainings and outstanding needs <p>Timeline: ongoing trainings</p>	4.6 Very High	DCR / Colleen Ferber	<ul style="list-style-type: none"> ▪ 3 training sessions provided in 2007; ▪ 6 trainings provided in 2008 ▪ Cancer Registrars surveyed in June 2008 ▪ 4 trainings planned for 2009 based on survey results <p>Assigned Tasks 1/2009:</p> <ul style="list-style-type: none"> ▪ Report back to DCRAC on training plan for 2009 (Colleen Ferber) ▪ Bring example training module to next DCRAC meeting (Colleen) 	In progress
<p>3b. Incentives for CTRs and hospitals with good data: rewards for CTR certification, bonuses for outstanding reporting, recognition of good hospital registry reports and studies</p> <ul style="list-style-type: none"> ▪ Encourage hospitals to support certification <p>Timeline:</p>	3.8 Med	DCR / Colleen Ferber	<ul style="list-style-type: none"> ▪ NCRW April 2007: DCR presented awards to hospital cancer registries for excellent data quality, timeliness and casefinding. ▪ NCRW April 2008: DCR presented awards to hospital cancer registries for excellent data quality and timeliness. Recognition of new CTRs within past year. <p>Assigned Task 1/2009:</p> <ul style="list-style-type: none"> ▪ Next DCRA meeting, January 2009 – Ask registrars for input on meaningful kinds of incentives and recognition awards; report back to DCRAC (Colleen Ferber) 	In progress
<p>3c. Provide funding for hospitals/registrars to attend national meetings (e.g. NCRA), as incentive for excellent quality/completeness of cancer data reporting</p> <ul style="list-style-type: none"> ▪ DPH Request budget from DCC/Advisory Council <p>Timeline:</p>	3.9 Med	DCR & DCRAC	No progress to report	Unmet

Strategy Three, continued - Provide more support to hospital cancer registries/cancer registrars ..

How Do We Measure Success?

- Reduced vacancy rates (CTR)
- % certified
- Survey hospital Cancer Registrars re: perceived value of trainings so far, and outstanding needs – Survey performed in June 2008
- # trainings - Increased trainings by DCR for hospital cancer registrars - **3 provided in 2007; 6 provided in 2008**

Strategy Four - Increase use of data to answer research questions

Action Step	Priority	Accountability	Progress	Status
4a. PR for DCR, emphasis on data quality to stakeholders <ul style="list-style-type: none"> ▪ Utilize DCR Newsletter; Get help from CCHS to release newsletter more frequently Timeline:	3.2 Low	DCR/ Betsy / CCHS	DCR Newsletter includes results of incidence data submissions to NAACCR and NPCR Assigned Task 1/2009: Set up conference call with Bob McBride, Bill Schmidt & Betsy Cromartie to discuss assistance with newsletter (Dr. Petrelli)	In progress
4b. Publicize availability of data for this purpose, e.g., through DE Medical Society publications, hospital medical record staff meetings, meetings of other interested groups/organizations – post newsletter on DE Medical Society website Timeline: on hold until law is passed	2.7 Low	DPH/State PR	DCR Newsletter March 2008 - section on data requests	In progress
4c. Publish data access guidelines/P&Ps to assure consistent response to data requests (This is already on DPH web site) Timeline: on hold until law is passed	2.9 Low	DCR/DPH	State implemented policy	In progress

Strategy Four, continued - Increase use of data to answer research questions.

Action Step	Priority	Accountability	Progress	Status
<p>4d. Develop capacity to assist data users with the inevitable questions which will arise; e.g. an on-line FAQ resource, a contact person/position, a subject matter expert to whom particularly thorny questions can be directed – utilize state website – add newsletter, manuals, useful links, DCRAC minutes.</p> <p>Timeline: on hold until law is passed</p>	<p>2.9 Low</p>	<p>DCR/DPH</p>	<p>No progress to report</p>	<p>Unmet</p>

How Do We Measure Success?

- # of data requests –**Increase in requests: 41 data requests received by DCR in 2006; 71 data requests in 2007; 65 requests in January – September of 2008**
- # of research projects – **Projects using cancer registry data are currently in development: Using claims data to investigate time-to-treat issues; CRC Stage III/chemo chart review study; Indian River Community Survey; Census County Division Project investigating cancer cluster patterns;**
- Time to fulfill requests –**Requests currently filled in timely manner, the majority within 2 days**
- Hits on website/WebTrends traffic analysis
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Strategy Five - Change Delaware Cancer Control Act and Regulations Regarding DCR

Action Step	Priority	Accountability	Progress	Status
5a. Change Delaware Cancer Control Act to Eliminate Occupation & Residency Data Collection Requirement Timeline:	4.3 High	DCRAC	<ul style="list-style-type: none"> Submitted recommendations to Governor's attention for consideration in 2007 and in 2008 January 2008 decision by Governor's office – change in legislation not approved <p>Assigned Task 1/2009: Draft is ready, will need DCRAC to advocate for change in law with new administration</p>	In progress
5b. Clarify definition of benign brain/CNS tumors in Delaware Cancer Control Act	4.0 Med	DPH	<ul style="list-style-type: none"> September 2008 - Decision made not to change regulations. Reportable cancer list posted on DPH Cancer Control webpage. December 2008 - Link to reportable list included on Medical Society of Delaware website 	DONE
5c. Determine feasibility/desirability of implementing regulation requiring submission of treatment data along with other follow-up information Timeline:	3.8 Med	DCR & DCRAC	<p>Assigned Task 1/2009: Contact DCR software vendor regarding technical issues of collecting follow-up treatment data (Betsy Cromartie)</p>	In progress
5d. Advocate for a law to release data to researchers Timeline:	3.8 Med	DCRAC	<ul style="list-style-type: none"> Confidential requests processed through HSRB, using PM 49 of DE DPH Division submitted recommendation to the Department to change law as part of Governors legislative agenda 	In progress

- How Do We Measure Success?** New Law – Will need to postpone 5a. until the next administration as we are unlikely to make progress with the current administration.

Strategy Six - Develop routes of efficient communication between the registry and its stakeholders: especially with healthcare practitioners and facilities, interested agencies, and the public. Better, clearer communication of reporting requirements. Better communication of the benefits of the DCR to the public.

Action Steps	Priority	Accountability	Progress	Status
<p>6a. Develop a brief, clear “Guide to Reporting Requirements” for distribution to those people/places required to report under the Cancer Control Act.</p> <ul style="list-style-type: none"> ▪ Revise reporting manuals annually; get feedback on manuals from surgicenters, hospital, others. Post on DCR website. <p>Timeline:</p>	4.0 Med-High	DCR / Betsy Cromartie	<p>January 2008 - DCR Hospital and Non-Hospital Reporting Manuals updated and distributed</p> <p>Assigned Task 1/2009: Review current requirements and revise manuals as needed (Betsy Cromartie)</p>	In progress
<p>6b. Develop companion Power Point slideshows that can be presented when opportunities arise to inform providers, the public, or others about the Registry</p> <ul style="list-style-type: none"> ▪ Get generic presentation from national agency, e.g. COC, NAACCR, NPCR, NCRA and then tailor to DCR needs <p>Timeline:</p>	3.4 Low	DCR/DPH	No progress to report	Unmet
<p>6c. Develop DCR website</p> <p>Timeline:</p>	3.8 Med	DCR/ Crystal English	<ul style="list-style-type: none"> ▪ August 2008 – Macro developed draft webpage and subpage design for approval by the DCRAC. Draft pages presented to the DCRAC at September meeting. ▪ November 2008 – Crystal English met with State web development staff & reformatted webpage layout, determined internal and external sites to link to, & identified documents to post on website. <p>Assigned Task 1/2009: Report progress back to DCRAC (Crystal English)</p>	In progress

Strategy Six, continued - Develop routes of efficient communication between the registry and its stakeholders: especially with healthcare practitioners and facilities, interested agencies, and the public. Better, clearer communication of reporting requirements. Better communication of the benefits of the DCR to the public.

Action Steps	Priority	Accountability	Progress	Status
6d. Make public NAACCR and NPCR findings regarding certification/quality of DCR data, e.g. post on DCR website. Timeline:	3.8 Med	DCR/DPH	Included in DCR newsletter	In progress

How Do We Measure Success?

- Professional articles/publications (e.g. CRC Stage III study)
- Ads in journals *Pamphlets drafted
- Newsletters released regularly, posted on website– **4 editions of DCR newsletter issued in 2007-2008, to date**
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- * Meetings
- *Hits on DCR website