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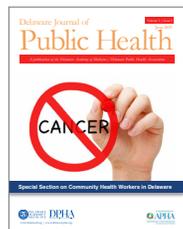
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COVER

The world's oldest case recorded case of cancer is from Egypt in 1500 BC, describing breast cancer. It states there is no cure, only palliative treatment. As today, surface tumors were surgically removed.

3517 years later we have progressed significantly in the diagnosis, treatment, and understanding of cancer – but there is still much work to be done.

The Delaware Journal of Public Health (DJPH), first published in 2015, is the official journal of the Delaware Academy of Medicine / Delaware Public Health Association (Academy/DPHA). **Submissions:** Contributions of original unpublished research, social science analysis, scholarly essays, critical commentaries, departments, and letters to the editor are welcome. Questions? Write djph@delamed.org or call Liz Healy at 302-733-3989. **Advertising:** Please write to ad@delamed.org or call 302-733-3989 for other advertising opportunities. Ask about special exhibit packages and sponsorships. Acceptance of advertising by the Journal does not imply endorsement of products. Copyright © 2017 by the Delaware Academy of Medicine / Delaware Public Health Association. Opinions expressed by authors of articles summarized, quoted, or published in full in this journal represent only the opinions of the authors and do not necessarily reflect the official policy of the Delaware Public Health Association or the institution

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IN THIS ISSUE



Daniel J. Meara, M.D., D.M.D.
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Opportunities for meaningful collaboration abound in the fields of medicine and public health. The challenge comes in identifying the right partners, at the right time, with common goals to create a true “win-win” scenario for all concerned. Sometimes, these potential partners become visible through something as simple as a name change. Such is the case with the National Academy of Medicine (NAM) (formerly the Institute of Medicine).

Over the past year, we were able to meet with our colleagues at the NAM, discern a path towards collaboration, and invite NAM President Victor J. Dzau, M.D. to give the Delaware Academy of Medicine’s Annual Meeting keynote address in May. His presentation “Vital Directions for Health and Medicine: Priorities from a National Academy of Medicine Initiative” was heard by over 150 leaders in both the healthcare and public health sectors in Delaware. The Academy looks forward to developing our relationship with the NAM, bringing their expertise to Delaware, and engaging in a novel state/national collaborative relationship with this esteemed institution. (Read more about Vital Directions here) <https://nam.edu/vital-directions-for-health-health-care-priorities-from-a-national-academy-of-medicine-initiative/>

We look forward to developing our relationship with the NAM, bringing their expertise to Delaware, and engaging in novel state/national partnership with this esteemed institution.

The annual meeting is also the vehicle for presenting the Lewis B. Flinn President’s Award, and the Executive Director’s Public Health Recognition Award to worthy recipients. This year’s President’s award recipient was the Honorable Susan P. Del Pesco, Esq., and the Public Health Recognition Award was presented to the American Lung Association of the Mid-Atlantic, and their President and CEO, Deborah P. Brown.



**Keynote Speaker
Victor J. Dzau, M.D.**
President,
National Academy of Medicine



**Susan Del Pesco, Esq. at the
podium after receiving the
Lewis B. Flinn
President’s Award**



**Deborah P. Brown,
receiving the Public Health
Recognition on behalf of the
American Lung Association
of the Mid-Atlantic**

Additional pictures from the 2017 Annual Meeting, as well as our Year in Review, can be viewed online at www.delamed.org.

In this issue of the Delaware Journal of Public Health, we address the critically important areas of Cancer. We are honored to have Nicholas J. Petrelli, M.D., Bank of America Endowed Medical Director, Helen F. Graham Cancer Center & Research Institute of Christiana Care Health System, as our guest editor. We know you will appreciate the wealth of expertise in these pages.

As always, we welcome your feedback and comments.

Cancer Care in Delaware: A National Model

This issue of the Delaware Journal of Public Health is devoted to cancer.



Nicholas J. Petrelli, M.D., F.A.C.S., is the Bank of America endowed medical director of Christiana Care Health System's Helen F. Graham Cancer Center and Research Institute.

In January of 2017, I was interviewed by Michael Nedelman from CNN. I related that despite being the second smallest state, Delaware had the highest rate of cancer deaths in the country during the early 1990's. This certainly was not a top ten list you wanted to be listed on. However, that all started to change in 2001 largely due to the Delaware Cancer Consortium established by Governor Ruth Ann Minner and directed by William Bowser, Esq. Aside from several of the manuscripts in this issue of the Journal that have contributed to the decline in cancer mortality, I would like to discuss programs that are not in this issue that have led to the cancer mortality rate in Delaware continuing to drop twice as fast as the national average. There is no question that the model in Delaware for cancer care and prevention can be replicated in any state in the country.

The contents in this issue of the Journal discuss many aspects in the cancer care arena. They span from the American College of Surgeons Commission on Cancer outcome measures, to improving access to cancer genetic counseling through telegenetics, to the psychosocial care for patients with cancer and, of course, a brief discussion of the Delaware Cancer Consortium and the Delaware Cancer Treatment program. The latter is an example of national cancer health insurance covering all cancer patients in the state.

However, it is important for readers of the Journal to understand that major efforts have occurred over the last decade that have resulted in a projection made by the American Cancer Society, dropping the state of Delaware to number 18 in cancer mortality in the United States in 2017. I'd like to discuss several programs that have contributed to this cancer mortality decrease. The first is the grant funded National Cancer Institute Community Oncology

Research Program (NCORP) under the direction of Gregory Masters, M.D. and Kandie Dempsey, DBA, MS, RN, OCN, at the Helen F. Graham Cancer Center and Research Institute. This program together with the Tunnel Cancer Center at Beebe Hospital and Nanticoke Hospital has given patients access to over 100 clinical trials in areas of treatment, cancer control, prevention, translational cancer research and trials available through the pharmaceutical industry. Because of this nationally recognized program, patients receive better care on clinical trials. It is also important to note that all the physicians that participate in these trials do so on a voluntary basis without receiving any financial support.

Another major program in the state is the High Risk Family Cancer Registry at the Helen F. Graham Cancer Center and Research Institute under the direction of Zohra Ali-Khan Catts, MS, CGC. Prior to 2002, there was not one full-time adult genetic counselor in the state of Delaware. Following the recruitment of Zohra Ali-Khan Catts in 2002, this statewide program under her direction has five full-time genetic counselors. These counselors travel to Kent County, specifically, to the Tunnel Cancer Center at Beebe Hospital and Nanticoke Hospital, so patients can undergo genetic counseling and gene testing close to their own cancer centers and hospitals. This family cancer risk assessment program is the first and only one that is statewide. The High Risk Family Cancer Registry has over 8,253 individuals with over 250,000 family members. It also has a biorepository of 690 samples for translational cancer research under an Institutional Review Board protocol. This genetic counseling program is the ultimate in cancer prevention. These talented genetic counselors have the ability to take detailed family histories and then counsel and gene test individuals at high risk for developing cancer. Subsequently patients can be

counseled for prophylactic surgery, chemoprevention, or increased screening starting at a younger age than the general population. Also under the leadership of Zohra Ali-Khan Catts, State Bill #259 was passed in Delaware on June 30, 2010 which requires the licensing of all genetic counselors in Delaware. In January of 2017, Zohra Ali-Khan Catts in conjunction with colleagues at Thomas Jefferson University successfully completed an application for an accrediting program for an advanced degree in genetic counseling. There are only 37 genetic counseling training programs in the United States. A Task Force led by Zohra is now preparing for a Medical Center of Genetics at the Helen F. Graham Cancer Center and Research Institute to encompass all areas of genetics in prenatal, adult, cancer, cardiovascular, neurology and other clinical areas.

There is no question that when it comes to cancer care there are disparities. The establishment of robust community cancer outreach programs in the Hispanic, African American, Asian and Hindu communities is a model in the state for addressing small scale disparities. Outreach programs in all the cancer centers in the state and the Federally Qualified Health Care Centers are working hard to end the disparities in cancer care. These programs over the past 15 years through the Center for Disease Control Screening for Life grant have produced more than 48,000 breast cancer screenings, more than 44,000 cervical cancer screenings and more than 4,900 colonoscopies. Under the direction of Stephen Grubbs, M.D., Chair of the Early Detection and Prevention Committee of the Delaware Cancer Consortium and Nora Katurakes, RN, MSN, OCN, Director of Cancer Outreach at the Helen F. Graham Cancer Center and Research Institute, a statewide program of colorectal screening for all Delawareans 50 years of age and older started in 2001. This program resulted in Delaware's mortality in colorectal cancer to decrease by 30% from 1999-2001 to 2010-2011. A greater drop in the mortality rate was seen among African Americans compared to Caucasians (55% versus 23%). Importantly, in 2008 the disparity between African Americans and Caucasians in colorectal screening ended due to this statewide colorectal screening program. The Early Detection and Prevention Committee of the Delaware Cancer Consortium in April of 2015 took on the second statewide screening program in lung cancer based on the National Cancer Institute Phase III clinical trial which demonstrated a 20% decrease in lung cancer mortality with low dose CT scanning in patients meeting the criteria of a 30-pack year history of cigarette smoking.

Cancer care is multidisciplinary. It is not only the combined knowledge of the major disciplines of medical, surgical, and radiation oncologists, but all of the subspecialties that are necessary for high quality cancer care. In 2002, the first of 14 multidisciplinary disease site centers was established at the Helen F. Graham Cancer Center and Research Institute. At these multidisciplinary disease site centers, a patient and their family members are seen by a team of experts consisting of medical, radiation, and surgical oncologists along with subspecialties dependent on the disease site. For example, in the head and neck multidisciplinary center, aside from the three major disciplines, there also is a dentist, speech therapist, psychologist, nurse navigator, nutritionist, and clinical trials nurse. It is important to note that the nurse navigators and clinical trial research nurses are members of all of the multidisciplinary disease site centers. Patients receive their treatment plan in one visit as opposed to waiting three to four weeks to establish a plan. Cancer care is not only multidisciplinary, but it is very complex and having a high quality team approach to cancer care leads to better outcomes.

Lastly, I would be remiss if I didn't mention the partnership that the Helen F. Graham Cancer Center and Research Institute has with the Wistar Institute in Philadelphia. This partnership, which began four years ago, has led to translational research programs for Delawareans in a collaboration between clinicians at the Helen F. Graham Cancer Center and Research Institute and scientists at the Wistar Institute. This collaboration has provided the opportunity to bring cutting edge research into the community, creating strategic value for both organizations with strong joint institutional commitment. The Center for Translational Cancer Research at the Helen F. Graham Cancer Center and Research Institute, along with the work of scientists such as Eric Kmiec, PhD, who established the Gene Editing Institute, and the research of Bruce Boman, M.D., PhD in cancer stem cells for colorectal cancer, as well as the research of Jennifer Sims-Mourtada, PhD in triple negative breast cancer in the African American population, collectively demonstrate that an independent academic hybrid community cancer center can make major contributions to the diagnosis and treatment of cancer.

In view of the manuscripts in this edition of the Journal related to cancer care and the description of the programs described above, there should be no doubt in anyone's mind that Delaware continues to serve as a

model for successful cancer care and prevention. The Delaware Cancer Consortium and collaborative efforts of all cancer centers/hospitals, Federally Qualified Health Care Centers, the Delaware Breast Cancer Coalition, American Cancer Society and the Cancer Support Community, continue to move forward in problem areas of cancer care and prevention. Although a lot of hard work and effort remains, there is no question that the future cancer care of all Delawareans is in good hands. Politicians and business people in the state of Delaware need to take a hard look at this statewide model of cancer care and prevention which in less than a decade has dropped Delaware out of the top ten in cancer mortality. They should be looking to do the same in other areas of health care in our state, including obesity, mental health, drug addiction and homicides.

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Lieutenant Governor Bethany Hall-Long, at right, and Division of Public Health Director Dr. Karyl Rattay, center, thank ab+c for their work on the refreshed "Help is Here" website. Pictured at the website's May 23 re-launch are ab+c representatives, from left: Jason Trojanowski, Alex Parkowski, Andrew Raftovich, and Paul Pomeroy.

DHSS, ab+c refresh the Help is Here website to assist all Delawareans

Delaware Health and Social Services (DHSS) re-launched Delaware's online resource for addiction prevention, intervention, treatment, and recovery information, HelpIsHereDE.com, on May 23. It will assist people struggling with addiction, their families, the community, and medical providers.

The new version is easier to navigate, can be translated into four languages (Spanish, Haitian Creole, French, and Chinese), is more mobile-device friendly, and offers updated information for community and medical providers. Its expanded video section features new and highly personal testimonials from individuals in long-term recovery, parents who have lost adult children to overdoses, a treatment provider, and a police officer.

"Prevention and intervention are key to battling addiction in our state," said Delaware Lieutenant Governor Bethany Hall-Long. "This is particularly true when it comes to our children. Stress, trauma, early exposure to drugs in the teen years, and early symptoms of a mental disorder can lead to addiction and mental illness. Making parents aware of and connecting them to supportive information through the 'Help Is Here' website is vital to preventing years of struggle with substance use."

The website address is www.helpisherede.com.



DELAWARE CANCER CONSORTIUM

The Delaware Cancer Consortium (DCC) was originally formed as the Delaware Advisory Council on Cancer Incidence and Mortality in March 2001 to advise the governor and legislature on the causes of cancer incidence and mortality and potential methods for reducing both. The DCC's work has helped our state improve in many areas, reducing incidence and mortality.



DELAWARE HEALTH AND SOCIAL SERVICES
Division of Public Health

The DCC is fully supported by the Division of Public Health (DPH) and led by volunteers who have a passion for improvement. We believe that anything is possible if you examine the facts, involve the right people, and develop an action plan. They – and the hundreds of others who work with them on projects – give their time, skills, and knowledge to make change happen.

The DCC:

- Maintains a permanent council, managed by a neutral party that reports directly to the governor to oversee implementation of the recommendations and comprehensive cancer control planning
- Serves as a leader and resource for Delawareans by informing the public through reports and the Healthy Delaware website about cancer prevention, early detection, and treatment
- Created and published multiple state cancer plans, most recently the 2012-2017 plan
- Oversaw the implementation of more than 30 recommendations in the past four years

First and foremost, the DCC's goal is to help people prevent cancer and detect it early. With cancer screenings, early detection is possible, giving people the best chance of fighting the disease effectively by identifying it when

*Heather Brown, Program Manager, Comprehensive Cancer Program,
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it's most treatable. The DCC has worked to spread the word about the screenings and created more opportunities for people to be screened through special programs such as Screening for Life. Most importantly, since lung cancer continues to account for an enormous share of Delaware's overall cancer burden,

**screening
for life**

the DCC recommends offering low-dose computerized tomography (CT) scans to smokers and former smokers. From 2008–2012 (Delaware Division of Public Health, 2016), lung cancer accounted for 14.4 percent of all newly diagnosed cancer cases and 30.0 percent of all cancer deaths in Delaware. This screening is expected to find cancer when it can be treated, helping people to overcome the disease by finding it at an early stage.

The DCC's landmark program, the Delaware Cancer Treatment Program, continues to provide cancer treatment for 24 months to any Delawarean who qualifies. This program – the first of its kind in the nation – continues to evolve as we work to fill identified gaps, helping Delawareans get the cancer treatment they need.

The DCC has made significant progress in their goal to eliminate the inequality in Delaware's cancer burden for the period 2008–2012. Among African Americans, lung cancer, breast cancer, and colorectal cancer deaths are down. Colorectal cancer is down 50 percent for men and 45 percent for women. The grassroots efforts to make the African American community aware of the cancer threat – and the need for early detection through screenings – are making a difference.

Data, statistics about cancer in our state, is the foundation of knowledge for making changes that can save and improve lives. We continue to forge relationships with facilities and organizations that can provide us with accurate data to expand and enhance our understanding



of cancer diagnosed among Delaware’s many demographic and geographic regions. With the support of DPH, the DCC uses Delaware Cancer Registry data to create maps. The maps identify areas with statistically significant late-stage diagnosis of breast and colon cancer, allowing them to target education and awareness in those areas.

Improvements in Delaware’s cancer incidence and mortality for the time period 1998–2002 to 2008–2012 (Delaware Division of Public Health, 2016) include:

- The overall cancer death rate decreased 14.0 percent, an improvement that was similar to the national decline (14.0 percent).
- Lung cancer mortality rates declined 32.6 percent among African American men and 23.7 percent among African American women.
- Female breast cancer mortality declined 22.3 percent, which was greater than the national decline (17.4 percent).
- African Americans showed a greater rate of decline in female breast cancer mortality than Caucasians (27.2 and 20.7 percent, respectively).
- Prostate cancer mortality declined 39.2 percent among African American Delawareans, compared to 23.3 percent among Caucasian Delawareans.
- Colorectal cancer mortality rates declined 49.7 percent among African American men, compared to 29.3 percent among Caucasian men.
- Colorectal cancer mortality declined 44.6 percent among African American women, compared to 29.0 percent among Caucasian women.

For the time period 2008–2012, improvements in Delaware’s cancer screening, incidence and mortality (Delaware Division of Public Health, 2016) include:

- The colorectal cancer incidence rate among African Americans in Delaware (41.4 per 100,000) was lower than the U.S. rate (52.3 per 100,000). This difference is statistically significant.
- In 2014, Delaware ranked fifth highest in the United States for colorectal cancer screenings, with 76.5

percent of Delawareans age 50 and older reported having had a sigmoidoscopy or colonoscopy, according to the 2014 Behavioral Risk Factor Survey (BRFS).

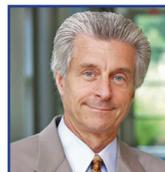
- A decline in female breast cancer mortality (22 percent) was 29.4 percent greater than the national decline (17 percent).

It has been more than a decade since the DCC began its quest to lower cancer incidence and mortality rates in Delaware. The DCC realizes cancer is a complex disease and there is no one silver bullet. The ultimate goal is to work toward having the lowest cancer incidence and mortality rates in the nation. DCC members want to ensure that Delawareans who are diagnosed with cancer receive the best possible care in an efficient, person-centric way. As the DCC moves forward, it will educate Delawareans about the risk factors for cancer, such as being physically active and quitting tobacco use. Members will also continue work to identify and address the root causes of racial and ethnic disparities in cancer incidence and mortality in Delaware.

The reason is obvious. With every change, the DCC may save another life.

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Nicholas J. Petrelli, M.D., F.A.C.S., is the Bank of America endowed medical director of Christiana Care Health System’s Helen F. Graham Cancer Center and Research Institute.



Heather Brown started her career in Public Health in 2008 where she worked in the Screening for Life program within the Chronic Disease Bureau of the Health Promotion Disease Prevention Section. In 2010, she moved onto Family Health Systems in the Center for Family Health Research as the PRAMS data manager and in 2011 moved on to manage the budget of the Center which included the infant mortality and PRAMS programs, as well as the Delaware Healthy Mother and Infant Consortium. After 3 years in Family Health, Heather rejoined the Chronic Disease Bureau in March 2013 as the Comprehensive Cancer Control Program Director. As the Comprehensive Cancer Control Program Director, Heather manages the Cancer Program, the Delaware Cancer Treatment Program, and the Delaware Cancer Registry. She also provides oversight to the Delaware Cancer Consortium. Her interest and dedication to the cancer field comes from a number of family members and close friends that have been faced with the disease. With that in mind, she has committed herself to educating Delawareans on ways to prevent cancer and other chronic diseases by knowing their risk factors and encouraging them to talk to their healthcare provider about recommended screenings.



Improving Access to Cancer Genetic Counseling through Telegenetics - A Bayhealth - University of Pennsylvania Initiative

Cara Cacioppo¹, Neeraja Reddy (co-authors), Elisabeth M. Wood¹, Jan Jaeger¹, Demetrios Ofidis¹, Rishi Sawhney², Priya Singh², Kimberly Vidrine², Harriet Pinkston², John Shevock², Angela Bradbury¹

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The authors have no conflicts of interest to disclose.

Genetic testing for hereditary cancer syndromes, such as BRCA1/2 testing for Hereditary Breast and Ovarian Cancer syndrome, may have significant implications for patients and their families for cancer treatment, management, and prevention. The National Accreditation Program for Breast Centers now requires access to cancer risk assessment and genetic testing when appropriate for patients (Cancer Program Standards 2012). Traditionally, cancer genetics services have included in-person pre- and post-test genetic counseling (GC) with an experienced provider. Remote two-way video-conferencing (RVC) is a feasible alternative to provide genetic counseling for patients in geographically underserved populations with reduced travel burden. This alternative to traditional face-to-face counseling is also associated with high patient satisfaction and favorable cognitive and affective outcomes (Bradbury et al., 2016).

A majority of the genetic counseling workforce is centered in academic and urban centers which may require patients to travel long distances to receive in-person services. Limited access to genetics services creates potential disparities in clinical care (Armstrong J et al., 2015). In order to receive cancer genetic services, Bayhealth Medical Center (BHMC) patients were referred to major medical centers located outside

of the southern Delaware region. Barriers, including the time and cost of travel as well as unfamiliarity with these outside centers, resulted in reduced uptake of genetic counseling and testing for patients and families with significant cancer history. BHMC has partnered with the Penn Telegenetics Program at the University of Pennsylvania to make genetic counseling accessible on-site, eliminating the need for patients to travel long distances and maintaining continuity of care within the BHMC network.

Penn Telegenetics Program at Bayhealth Medical Center

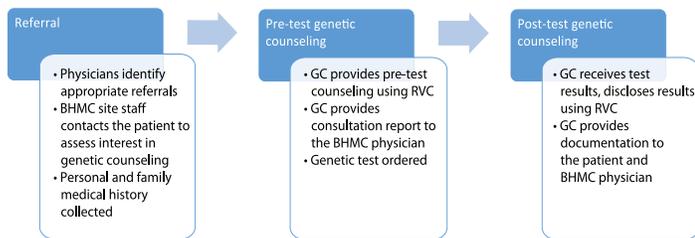
The Penn Telegenetics Program provides cancer genetic counseling services using RVC to community hospitals without access to genetic providers. BHMC was a participating site in a NIH-funded pilot-study conducted at the University of Pennsylvania, investigating the feasibility of using RVC cancer genetic services at three community practices. At the conclusion of the study, BHMC entered into a clinical contract with the Penn Telegenetics Program to maintain continuity of telegenetics services. Genetic counselors at the Penn Telegenetics Program remotely provide genetic counseling using RVC to patients located at BHMC. They work closely with on-site physicians and staff to coordinate the genetic test

order and provide follow-up care when appropriate.

Serving the Community

When a physician in the community determines that a patient might benefit from genetic counseling,

Figure 1: Telegenetics Program Workflow



the patient can be referred to a Penn Telegenetics counselor (Figure 1). The types of referrals might include: patients recently diagnosed with cancer who are considering treatment options, patients with a strong personal and/or family history of cancers, patients with young age of diagnosis and patients with personal and/or family history of rare cancers or other findings. Benefits of genetic counseling include personal assessment for inherited risk factors, discussion of genetic testing options and outcomes, education on early detection and risk-reduction options, as well as addressing patients' psychosocial concerns. Discussion of these topics further fosters informed decision making. Most genetic testing is covered by patient insurance for patients meeting specific criteria. Financial aid options are available for patients who do not receive insurance coverage. Telegenetics allows patients to receive quality care in their local community sites while reducing travel burden, costs, time and disruptions to their daily routine. In addition, local providers gain access to services and information without having to refer their patients outside of their practice.

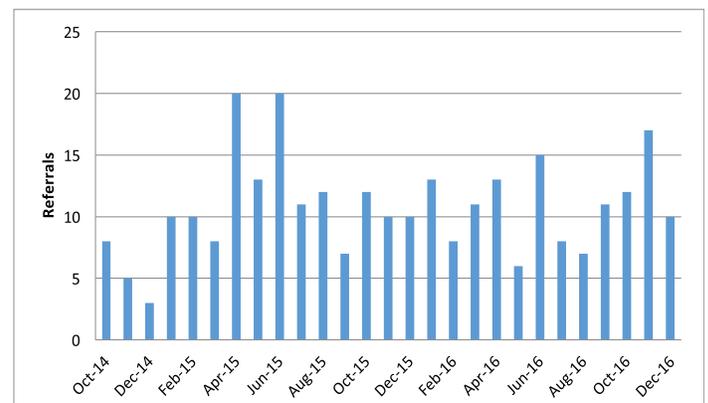
For many, access to telegenetics services may be invaluable, as the information may impact risk reduction and treatment options. This information may also benefit family members of patients. When an individual is found to have a gene mutation, family members are eligible for genetic counseling and testing to learn about their personal cancer risk. Through our services, we have identified families with several hereditary cancer syndromes, such as: Hereditary Breast and Ovarian Cancer syndrome, Lynch syndrome, Cowden syndrome, Li-Fraumeni syndrome, and other gene mutations conferring increased cancer

risk. These patients and their family members can now receive personalized screening and prevention options to manage increased cancer risk due to a gene mutation.

Telegenetics Program Overview

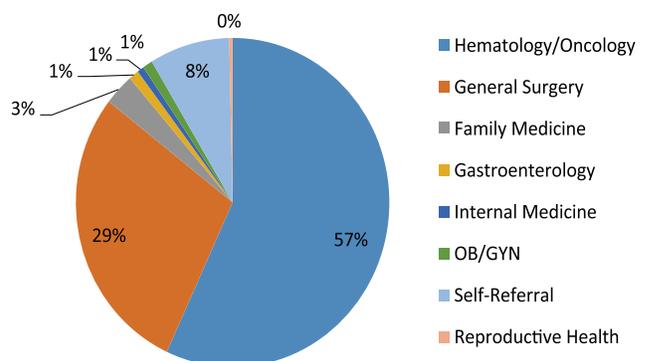
Since the start of the program, 290 patients have been referred by on-site physicians (n=178), local

Figure 2: Monthly referrals to the Telegenetics program at BHMC



community doctors (n=88) and self-referral (n=24)

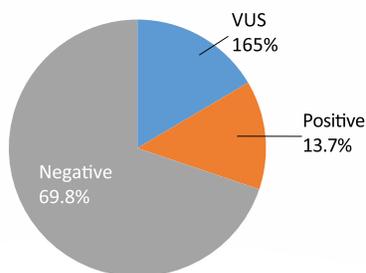
Figure 3: Referral Sources by Specialty



(Figure 2). The majority of referrals are from oncologists (57%) and surgeons (29%) (Figure 3). To date, 135 patients have been seen for pre-test counseling; of the remaining 155 referrals not seen for genetic counseling, reasons include patient refusal of services, lost to follow-up or pending decision to receive services. One hundred and nine patients elected to have genetic testing and completed disclosure sessions, resulting in the identification of 15 positive mutation carriers (Figure 4).

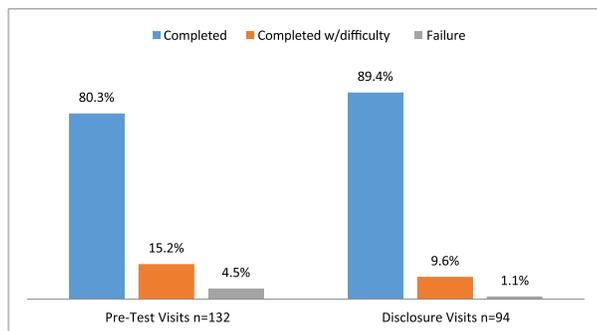
Patients are located at BHMC and connect with Penn genetic counselors using RVC platforms. To assess performance of technology used, data was obtained on 132 pre-test sessions and 94 post-test sessions. The majority of sessions were completed successfully

Figure 4: Summary of Genetic Test Results



(80% pre-test, 89% post-test). Technology disruptions occurred in some sessions (15% of pre-test and 9% post-test), and few sessions required a secondary RVC platform or telephone to be completed successfully

Figure 5: Videoconferencing Completion Rates



(4% pre-test and 1% post-test) (Figure 5). In addition, patients were offered the option of telephone services in some circumstances. Patients have verbally expressed high satisfaction with telegenetics due to ease of access, reduced travel burden and continuity of care in their community.

Conclusion

Knowledge about the presence of increased risk for cancer can provide important, sometimes life-saving options to patients, such as increased cancer screening, prophylactic surgeries, and personalized medication regimens. Previous studies have demonstrated that meeting with a genetic counselor increases patient knowledge, understanding and satisfaction (Moyer VA, et.al, 2014; Christie J, et.al 2012). The limits of in-person consultation become apparent as demand for genetic counseling increases. Penn Telegenetics and Bayhealth Medical Center strive to fill this gap efficiently, helping both patients and their physicians. We will continue our efforts to reach patients and families who may benefit from genetic counseling, and improve our services by implementing innovative approaches to care.

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Commission on Cancer (CoC) CP3R Measures for Colon Cancer Evaluation of Delaware Cancer Registry Data

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Abstract

This study evaluates the Delaware Cancer Registry's 2010–2014 colon cancer data using Cancer Program Practice Profile Reports (CP3R) quality of care measures developed by the American College of Surgeons Commission on Cancer. The CP3R measures assess: 1) the number of regional lymph nodes removed and pathologically examined for resected colon cancer (12RLN); and 2) the provision of adjuvant chemotherapy for Stage III patients (ACT). Research was conducted in the Delaware Health Information Network and with hospital cancer registries for cases missing values for provision of chemotherapy. Percentages of cases meeting the standard of care were calculated after stratification by sex and race.



Introduction

The Delaware Cancer Registry (DCR) is a state central population-based cancer registry, providing data for cancer surveillance and control initiatives of the Division of Public Health as well as statewide, national and international partners. DCR data meet the standards for data quality, timeliness, and completeness of the Centers for Disease Control's National Program of Cancer Registries (CDC-NPCR) and the North American Association of Central Cancer Registries (NAACCR). An assessment of quality of cancer care using DCR data was undertaken to determine: a) whether the data could be used to evaluate the statewide level of adherence to standard of care measures currently used by Delaware hospitals accredited by the Commission on Cancer and, if so, b) to what extent are the cases in the DCR compliant with the current standard of colon cancer care measures.

Background on RQRS and CP3R - Quality Cancer Tools of the Commission on Cancer

Currently, seven Delaware hospitals have Commission on Cancer (CoC)-accredited cancer programs. The National Cancer Database of the CoC provides a number of tools for use by CoC-accredited cancer programs to evaluate and compare cancer care at their facility with that provided at the state, regional, and national levels. One of these tools, the Rapid Quality Reporting System (RQRS), is designed to be a "close-to-real-time" reporting and alert tool to promote national evidence-based cancer care at the local community level¹. The RQRS utilizes a web-based, systematic data collection and reporting system to promote evidence-based therapy through a web-based prospective alert system for anticipated care. Utilizing the RQRS enables CoC-accredited cancer programs to evaluate data on patients concurrently, notifying hospitals of treatment expectations, and showing a hospital its year-to-date concordance rate relative to the state, other similar hospitals, and hospitals at the national level. RQRS currently evaluates four breast measures and two colon measures. While RQRS participation has been voluntary, beginning in January 2017, all CoC-accredited cancer programs are required to participate².

Another tool to promote evaluation and improvement of quality of cancer care is the CoC's Cancer Program

Practice Profile Reports (CP3R). CP3R displays a hospital's record of care, which is used to promote continuous improvement of patient care and enables hospitals to compare adherence to quality of care standards with those of other providers³. The CP3R currently reports twenty-three quality measures covering ten primary cancer sites. The two CP3R measures for quality of colon cancer care are the focus of this study using statewide cancer registry data.

Evaluation of Delaware's Cancer Data - CP3R Colon Cancer Measures

One objective of the Delaware Cancer Registry Advisory Committee (DCRAC) is to improve the quality of Delaware's cancer data to enable evaluation of treatment practices against patient outcomes. Toward this objective, the DCRAC promoted usage of the RQRS in Delaware hospitals over the past several years. To assess the feasibility of reporting on quality of care measures for Delaware cancer data as a whole, the Commission on Cancer's CP3R 12 Regional Lymph Nodes (12RLN) and Adjuvant Chemotherapy (ACT) measures were evaluated for the Delaware Cancer Registry's colon cancer case data regarding adherence to the standard of care.

The CoC's case eligibility criteria for these measures were used to select subsets of analytic colon cancer cases diagnosed during the period 2010-2014 from the Delaware Cancer Registry (DCR) database.

Discussion

The CoC defines the first CP3R Measure, 12RLN, as "at least 12 regional lymph nodes are removed and pathologically examined for resected colon cancer."⁴ A clinical rationale for this measure, as noted in the American Joint Committee on Cancer's Cancer Staging Manual, 7th edition, is that the number of lymph nodes examined "has been reported to be associated with improved survival, possibly because of increased accuracy of staging."⁵ The CoC's 2016 expected EPR (estimated performance rate) for this measure is 85%.

An in-depth review of the cases showed that 89.77% had twelve or more lymph nodes removed during colon surgery. This is 4.77% higher than the national standard. There was nearly no difference between males and females. There was a difference when comparing cases by race. The white cohort was 4%

higher than all other races. None of these differences were found to be statistically significant. These are presented in Table 1.

TABLE 1:
DCR Colon Cancer Cases Treated with Surgery (Diagnosed 2010-2014) – CP3R 12RLN Evaluation

VARIABLE	BY SEX N (%)		BY RACE N (%)		TOTAL N (%)
	Male (N=538)	Female (N=518)	White (N=864)	Other (N=192)	N=1,056
Age (mean ± sd)	68.1 ± 12.9	70.4 ± 13.2	70.5 ± 12.7	63.6 ± 13.3	69.2 ± 13.1
Number of lymph nodes examined (mean ± sd)*	20.8 ± 11.0	22.1 ± 11.1	21.6 ± 10.8	20.7 ± 12.1	21.5 ± 11.1
Lymph nodes examined					
Yes	532(98.9)	509 (98.3)	854 (98.8)	187 (97.4)	1,041 (98.6)
No	5 (0.9)	9 (1.7)	9 (1.0)	5 (2.6)	14 (1.3)
Other/Unknown	1 (0.2)	0 (0.0)	1 (0.1)	0 (0.0)	1 (0.1)
Had at least 12 lymph nodes examined					
Yes	532(98.9)	509 (98.3)	854 (98.8)	187 (97.4)	1,041 (98.6)
No	5 (0.9)	9 (1.7)	9 (1.0)	5 (2.6)	14 (1.3)
Unknown	1 (0.2)	0 (0.0)	1 (0.1)	0 (0.0)	1 (0.1)
Vital Status					
Alive	386 (71.8)	384 (74.1)	617 (71.4)	153 (79.7)	770 (72.9)
Dead	152 (28.2)	134 (25.9)	247 (28.6)	39 (20.3)	286 (7.1)

*Only for those who had lymph nodes examined

The CoC defines the second CP3R Measure, Adjuvant Chemotherapy (ACT), as: “Adjuvant chemotherapy is recommended or administered within four months (120 days) of diagnosis for patients under the age of eighty with American Joint Committee on Cancer (AJCC) Stage III (lymph node positive) colon cancer.”⁴ The CoC’s clinical rationale is that “there are substantial data that there is underuse and wide variation in the use of chemotherapy with Stage III colon cancer.”³ There is currently no expected EPR for this measure.

Research using the Delaware Health Information Network (DHIN) and with Delaware hospital cancer registries was conducted to investigate cases with missing chemotherapy data (approximately 15% of the total), and the DCR database was updated as necessary.

The review of stage III colon cancer cases having adjuvant chemotherapy administered or recommended within four months of diagnosis showed 95% compliance. There were differences in the percentages between the genders and racial groups on this measure, as shown in Table 2. The percentage of males was approximately 3% lower than females, and the percentage of whites was approximately 4% lower than all other races. None of these differences were found to be statistically significant. There can be many factors that influence whether patients receive adjuvant chemotherapy such as co-morbid conditions, age, and patient willingness to undergo chemotherapy. These are presented in Table 3.

Table 2:

DCR Stage III Colon Cancer Cases Diagnosed in Patients less than 80 Years of Age (2010-2014) - ACT Measure Evaluation

VARIABLE	BY SEX N (%)		BY RACE N (%)		TOTAL N (%)
	Male (N=134)	Female (N=108)	White (N=190)	Other (N=52)	N=242
Age (mean ± sd)	61.7 ± 11.2	61.6 ± 10.9	63.0 ± 10.9	56.7 ± 10.2	61.7 ± 11.0
Time to chemo - days (mean ± sd)**	69.4 ± 35.5	67.9 ± 25.6	69.3 ± 32.3	66.9 ± 28.6	68.8 ± 31.5
Received Chemo					
Yes	112 (83.6)	88 (81.5)	154 (81.0)	46 (88.5)	200 (82.6)
No	18 (13.4)	16 (14.8)	30 (15.8)	4 (7.7)	34 (14.0)
Missing	4 (3.0)	4 (3.7)	6 (3.2)	2 (3.8)	8 (3.3)
Received Chemo within 120 Days (N=200)					
Yes	105 (93.7)	85 (96.6)	145 (94.2)	45 (97.8)	190 (95.0)
No	7 (6.2)	3 (3.4)	9 (5.8)	1 (2.2)	10 (5.0)
Vital Status					
Alive	91 (67.9)	91 (67.9)	137 (72.1)	38 (73.1)	175 (72.3)
Dead	43 (23.1)	43 (23.1)	53 (27.9)	14 (26.9)	67 (27.7)

**Patients receiving chemotherapy, but not within 120 days of diagnosis was due to patient comorbidities (n=7) and unknown reasons (n=3)

Table 3 presents reasons why patients did not receive adjuvant chemotherapy.

Table 3:

Reasons for those who did not Receive Chemotherapy

VARIABLE	NUMBER	
Age (mean ± sd)	69.7 ± 7.1	
Chemo Summary	Alive	Dead
Chemotherapy was not recommended/administered because it was contraindicated due to patient risk factors	5	8
Chemo was not administered because the patient died prior to planned or recommended therapy	0	5
Chemo not administered; recommended by physician but not administered as first course of therapy	1	0
Chemo was not administered – patient/family refused	10	5
Total	16	18

Limitations of the Study

DCR data submitted annually to the CDC-NPCR and to NAACCR meet all quality criteria established by these standard setting organizations; however, remaining limitations of this study are possible data field coding errors and data missing from the DCR database. A potential solution is to conduct a data quality review of a random sample of cases from the subset under evaluation to assess level of accuracy.

Conclusion and Future Study

In this pilot project, Delaware Cancer Registry data were evaluated using the CP3R measures for quality of colon cancer treatment, 12RLN and ACT. With additional research in the Delaware Health Information Network and with hospital cancer registries for data on chemotherapy provision, it was possible to prepare a complete CP3R ACT measure summary for Delaware. The DCR data were used “as is” without additional data collection to prepare the 12RLN report. From these results, the Delaware Cancer Registry Advisory Committee concluded that it is feasible to examine these measures using DCR data. The DCRAC plans to continue to encourage the use of the RQRS and the CP3R measures at the facility and state levels to improve quality of cancer data and most importantly, to improve quality of cancer care.

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Robert Hall-McBride, C.T.R., is a Certified Tumor Registrar with 23 years of cancer data experience in hospital registries, state central registries as well as department of defense registries. He is also a consultant for cancer programs in Delaware and the east coast.



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Betsy Cromartie, M.A., C.T.R. is the Project Manager at the Delaware Cancer Registry (DCR). She is a Senior Associate with ICF, providing contractual services for the Delaware Division of Public Health Comprehensive Cancer Control Program since 2004. Together with the DCR team, she provides cancer registry management and technical services, including data collection, information management, quality assurance and training. The DCR works with the Division of Public Health, cancer registrars and reporters from hospitals and non-hospital offices, the Delaware Cancer Registrars Association, the Delaware Cancer Registry Advisory Committee, other state central cancer registries and partners from national standard-setting organizations to assure that Delaware's cancer data is of excellent quality for use in cancer control initiatives.



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Nanoparticle-mediated Gene Regulation as a Novel Strategy for Cancer Therapy

Nicole L. Kreuzberger, Jilian R. Melamed, and Emily S. Day

In 2014, approximately 14.5 million Americans were either actively fighting cancer or survivors of cancer and this number is expected to increase in the coming years.¹ With this increasing prevalence, research for novel cancer treatments has become of the utmost importance. Current treatments for most forms of cancer include surgery to remove the cancerous cells, and chemotherapy or radiotherapy to cause cancerous cell death. Although these treatments are useful in many cancers, surgery is highly invasive, and chemotherapy and radiotherapy suffer from innate or developed resistance that promotes tumors' continued progression or later recurrence. Researchers are interested in developing new treatments that may be used alone or in combination with conventional therapeutic interventions to more effectively halt tumor growth and prevent recurrence. Gene regulation is a promising new strategy to achieve these goals.

Using gene regulation-based approaches, researchers can deliver nucleic acids into cancer cells to either induce the expression of tumor suppressor genes, which inhibit tumor growth, or suppress the activity of oncogenes, which promote tumor growth. The effective application of gene regulation therapy requires knowledge of the biology involved in each individual patient's tumor. It is believed that providing therapies that are personalized to the complex nature of each type of cancer and to each individual person will improve patient outcomes.² In order to deliver this personalized gene regulation-based treatment,

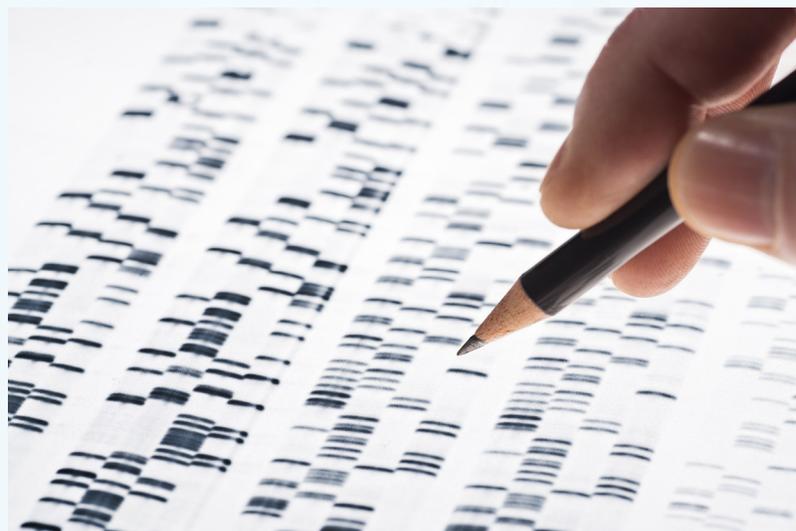
several different delivery vectors are currently in preclinical or clinical investigation. Viral vectors remain the most prevalent class of gene regulation agents in development and currently represent ~70% of all gene therapy clinical trials.³ Although viral vectors are highly effective as nucleic acid delivery vehicles, several shortcomings limit their success as therapeutics. For example, viral vectors can induce strong immunogenicity, which can produce flu-like side effects and limit the doses that may be administered.⁴ Nonviral vectors offer attractive solutions to these limitations. Synthetic, engineered nucleic acid delivery vehicles may be less immunogenic than viral vectors and can be more easily produced on a large scale to contain larger quantities of therapeutic nucleic acids.⁵ Such constructs can be engineered to deliver therapeutic nucleic acids including: (i) deoxyribonucleic acids (DNAs), which may either amplify gene expression or suppress the expression of target genes, depending on the nucleic acid design, (ii) messenger ribonucleic acids (mRNAs), which are single-stranded nucleic acids that encode the genetic instructions to produce specific proteins, and (iii) small interfering ribonucleic acids (siRNAs) or micro RNAs (miRNAs), which are short, double-stranded nucleic acids that suppress the expression of target genes in a sequence-specific manner.^{5,6} Here, we focus our discussion on the development of non-viral methods to deliver siRNA for RNA interference-based gene therapy, and include specific examples of research occurring at the University of Delaware.

RNA interference (RNAi) has recently emerged as a promising method to suppress the expression of cancer-promoting genes.⁷ In RNAi, siRNA that has been introduced into the cell associates with the RNA-induced silencing complex (RISC), which subsequently aligns with perfectly complementary mRNA to facilitate its degradation and prevent protein translation (Figure 1).⁸ The RNAi pathway offers several advantages as a strategy for gene regulation. For example, siRNA is highly specific and therefore may have fewer off-target effects than observed with standard chemotherapy and chemical oncogene inhibitors. Further, chemical oncogene inhibitors often rely on the presence of hydrophobic pockets that can be targeted within the protein structure. Many oncogenes lack such hydrophobic pockets and are consequently considered “undruggable.” Because RNAi inhibits oncogenes at the mRNA level prior to protein translation, these “undruggable” oncogenes can be silenced with siRNA.⁹

Although RNA interference is a promising method to treat cancer, naked siRNA must overcome several delivery barriers to be effective. For example, intravenously injected siRNA must travel through the blood to the desired tissue, penetrate the tissue and extracellular matrix, and enter the desired target cells.⁴ Although intravenous injection is an attractive approach to administer siRNA for its simplicity and non-invasiveness, siRNA is rapidly degraded by nucleases in the bloodstream.⁷ Additionally, siRNA is relatively large and negatively charged and therefore cannot passively enter cells, which have negatively charged membranes. Further, any siRNA that is taken up by cells faces an additional barrier to therapeutic efficacy. Specifically, endocytosed siRNA must escape the endosome to reach the cytoplasm since this is where mRNA resides.^{4,7} Due to the difficulty associated with delivering bare siRNA to cells, researchers are developing various types of carriers that can improve the circulation time, nuclease stability, cellular uptake, and cytoplasmic delivery of siRNA.^{4,7}

Much of the research that aims to improve systemic siRNA delivery focuses on creating nanoscale carriers that contribute to favorable behavior in physiological conditions. These carriers must be carefully designed with optimal physiochemical properties for efficient and tumor-specific siRNA delivery. In terms of size, the particles must be large enough to allow for sufficient doses of siRNA to be encapsulated within

or attached to the particle surface while remaining small enough to enter the cell. Typically, nanoparticles on the order of 20–200 nm in diameter are used to meet this criterion.^{9,10} Further, carrier materials must be chosen rationally to promote endosomal escape and gene regulation while minimizing toxicity to noncancerous cells. There are many types of carriers that are being researched that meet these criteria, each with advantages and limitations. We describe some of these below, and we also discuss research occurring at the University of Delaware in the labs of Dr. Emily Day, Dr. Millicent Sullivan, and Dr. Thomas Epps III, who are creating non-viral gene regulatory agents for enhanced cancer treatment.



One class of agents being investigated for siRNA delivery is “soft” materials, which include peptides, polymers, and lipids. For example, cationic cell-penetrating peptides (CPPs), such as TAT and Transportan, may be electrostatically complexed with negatively charged siRNA to create particles that are able to avoid endocytosis by forming pores in the cell membrane to deliver siRNA to the cytoplasm.^{10–12} Similarly, positively charged polymers can bind and condense negatively charged siRNA to protect it from degradation and facilitate cell uptake by endocytosis (Figure 2a).^{10,13} The mechanisms by which cationic polymer/siRNA complexes escape endosomes remain poorly understood, but may rely on endosomal osmotic swelling and subsequent rupture, releasing the endocytosed cargo into the cytosol.¹⁴ Within this carrier subtype, dendrimers are polymers with a highly organized branched structure that extends from a central core molecule, and they offer similar advantages in siRNA encapsulation and delivery.⁷ Finally, lipid-based particles such as liposomes (Figure 2b) and micelles are biocompatible and

biodegradable, and are currently the furthest along in clinical development. Positively charged lipid-based carriers can be tailored to effectively protect siRNA and promote endosome escape.⁷ For example, much recent research has focused on developing ionizable lipids, which become protonated to carry a net positive charge only in low pH conditions such as the interior of endosomes. Upon protonation, these ionizable lipid-based particles can fuse with the endosomal membrane to release their cargo into the cytosol and enable gene silencing.¹⁵



At the University of Delaware, Dr. Millicent Sullivan's lab is working in collaboration with Dr. Thomas Epps III's research group to design novel polymer structures to successfully deliver siRNA to cells.¹⁶⁻¹⁸ For example, they have developed a block co-polymer (BCP) formulation that can complex with siRNA and degrade in response to light to trigger intracellular release of the siRNA cargo.¹⁶ This BCP contains a cationic polymer region that electrostatically interacts with the siRNA, a photocleavable region that will cleave in response to ultraviolet light, and a polyethylene glycol region to impart stability and biocompatibility. This carrier is advantageous in that it can bind siRNA molecules to keep them inactive until they are released within the cell cytoplasm by triggering the polymer's degradation with ultraviolet light. By increasing light exposure time, the researchers have been able to tune the levels of mRNA knockdown achieved upon light-triggered siRNA release from 0 to 86 percent.¹⁶ In the future, the ability to provide cell-specific delivery of siRNA at specific points in time may enable improved treatment with reduced off-target effects. However, *in vivo* utility of these constructs may require the polymer design to be tailored to degrade in response to near-infrared (NIR) light, rather than ultraviolet light, since NIR light penetrates tissue more deeply than other wavelengths.¹⁹

The second major class of materials that is being widely investigated for siRNA delivery is metallic nanoparticles. Specifically, gold-based nanoparticles are of great interest due to their biocompatible, bioinert nature and ease of synthesis.²⁰ Unlike other materials, which may encapsulate siRNA, most gold nanoparticles (AuNPs) that are used as siRNA carriers are designed to display the siRNA on their surface since AuNPs are not typically porous. siRNA is typically loaded onto AuNPs by gold-thiol bonding.²⁰ Within this class of materials, spherical nucleic acid nanoconjugates (SNAs) have recently received much attention as siRNA delivery vehicles. SNAs consist of a gold core densely coated with a radially-oriented shell of siRNA (Figure 2c).²¹ This conformation promotes siRNA stability, reduces immunogenicity, and enhances cellular uptake despite the SNAs having a net negative charge.^{22,23} To date, SNAs have been used to suppress target gene expression in glioblastoma tumors²⁴ and in non-cancerous applications such as diabetic wound healing.²⁵ Additionally, SNAs have been found to be nontoxic in animal trials,²⁴ validating their continued development as effective siRNA delivery vehicles. Notably, SNAs targeting Bcl2L12, an oncogene that inhibits apoptosis, have recently been approved for human clinical trials in glioblastoma multiforme.²⁶ Preclinical studies performed by Dr. Emily Day, currently an Assistant Professor at the University of Delaware, with colleagues at Northwestern University, showed that SNAs that silence Bcl2L12 reduce the growth of orthotopic glioblastoma tumors in mice.²⁴ The planned clinical trial will be invaluable for demonstrating whether the promising effects observed in murine cancer models are consistent in human tumors.

In the past five years, research has demonstrated that there are sequence-specific design rules that must be considered to develop effective SNAs. For example, the cellular uptake of SNAs and the stability of siRNA on SNAs are influenced by the nucleotide content.^{27,28} Additionally, studies have shown that while SNAs can enter cells to regulate gene expression, they are relatively inefficient because a large fraction of endocytosed SNAs remain trapped in endosomes and are unable to escape into the cytoplasm to promote maximum gene silencing.²⁹ Dr. Emily Day's lab at the University of Delaware is actively investigating different methods to trigger SNAs' endosome escape, which would increase SNAs' potency. These investigations have revealed that coating SNAs with

positively charged polymers such as polyethylenimine improves their endosome escape relative to uncoated SNAs, and these modified SNAs can enable gene silencing at low particle doses.

Beyond SNAs, a separate class of gold-based siRNA carriers that is being developed by the Day lab and by other researchers is photothermally active siRNA nanocarriers. These nanocarriers consist of nanoparticles such as nanorods or silica core/gold shell nanoshells that are densely coated with siRNA. Upon activation with near-infrared light, these nanoparticles convert the absorbed energy to heat, which both ruptures endosomes and releases siRNA from the nanoparticles' surface to enable cytoplasmic siRNA delivery.³⁰⁻³² The ability to precisely control the exact timing and location of siRNA delivery with photothermally active nanoparticles holds much potential as a new area of investigation in the realm of gene regulation.

Overall, siRNA-mediated gene regulation has substantial promise as a treatment for many types of cancer. Although there are unresolved challenges to effective siRNA delivery, recent research with nanoscale carriers has demonstrated the ability to overcome these challenges, and we have highlighted a few types of these carriers here. While some siRNA nanocarriers are now transitioning into clinical trials,^{26,33} ongoing studies will continue to optimize material design to improve siRNA delivery to tumors for potent gene silencing. In the future these siRNA nanocarriers may ultimately be used to improve tumor eradication and extend patient survival.

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Figures and Figure Captions

Figure 1. Schematic depicting the process of RNA interference therapy. Ordinarily, DNA is transcribed into mRNA, which is then translated into protein. In RNA interference therapy, siRNA delivered into cells complexes with the RNA-induced silencing complex (RISC) and guides it to perfectly complementary mRNA molecules in the cell cytoplasm, which are subsequently degraded, thereby halting protein production. Using RNA interference to silence the expression of disease-promoting genes has substantial promise as a cancer treatment strategy.

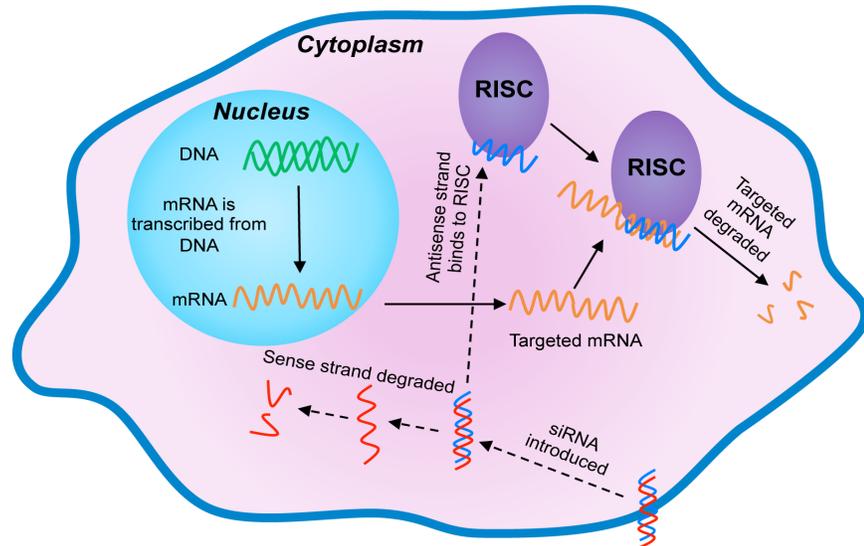
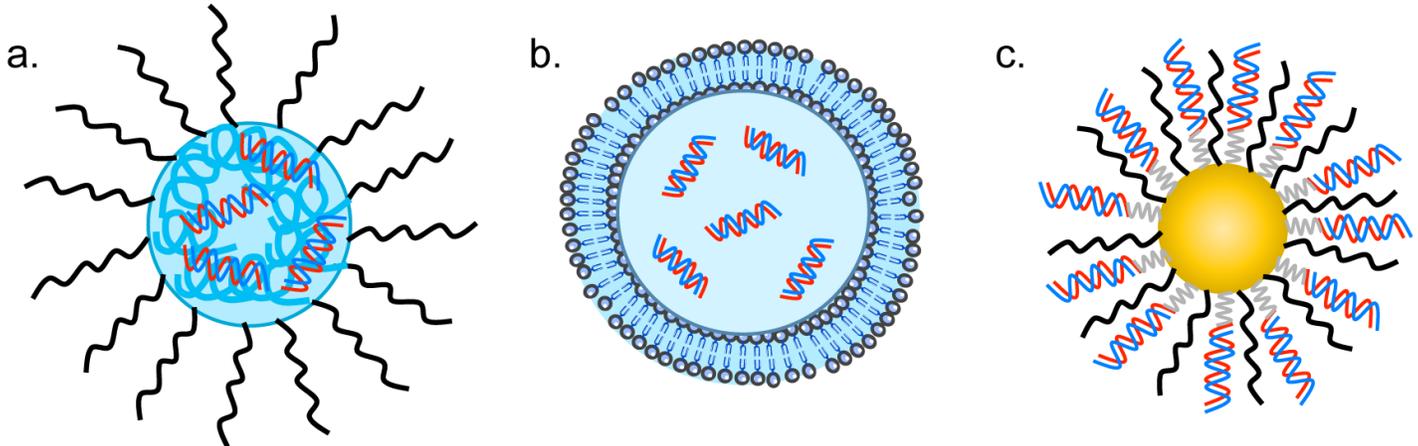


Figure 2. Examples of the types of nanoparticles used for siRNA delivery. (A) Polymers (light blue) can complex with and encapsulate siRNA (dark blue/red). Additionally, polymeric nanocarriers can be coated with stealthing agents such as polyethylene glycol (PEG, black) to enhance their stability and extend their circulation time in the blood. (B) Liposomal siRNA carriers consist of lipid bilayers that enclose siRNA inside the particle. (C) Spherical nucleic acids (SNAs) consist of gold nanoparticles densely coated with siRNA that is radially oriented away from the particle surface. SNAs are also coated with PEG for stability.



Nicole Kreuberger is a junior undergraduate student at the University of Delaware studying biomedical engineering. She has been working in Dr. Emily Day's laboratory in the Department of Biomedical Engineering at the University of Delaware since January 2016, assisting in synthesizing polymer-coated spherical nucleic acids for improved gene regulation. After graduating, she plans to pursue a career in industry.



Jilian Melamed is a Ph.D. student in the Department of Biomedical Engineering at the University of Delaware. Jilian received her Bachelor of Science degree in Biomedical Engineering from Rutgers University in 2013, and she currently works under Dr. Emily Day studying nanoparticle-based therapies to enable gene regulation in glioblastoma.



Emily Day, Ph.D., is an Assistant Professor of Biomedical Engineering at the University of Delaware. She received her B.S. in Physics from the University of Oklahoma in 2006, and her Ph.D. in Bioengineering from Rice University in 2011. She completed a postdoctoral fellowship in the Department of Chemistry at Northwestern University from 2011-2013 before joining the University of Delaware in 2013. Dr. Day's research group aims to transform the study, detection, and treatment of cancer with engineered nanomaterials.



Pediatric Perspectives 2017: Issues in Pulmonology, Infectious Diseases and Newborn Care

September 15 - 17, 2017
Atlantic Sands Hotel and Conference Center
Rehoboth Beach, DE

This conference is designed to provide pediatricians, family physicians, infectious disease specialists, pulmonologists, physicians-in-training, respiratory therapists and nurses with new perspectives on pediatric infections, pulmonary diseases and newborn care.

Topics Include:

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- Cystic Fibrosis- Update in Newborn Screening
- Common Referrals to the ID Clinic
- Cystic Fibrosis- Update in the Care of the Newly Diagnosed
- Chorioamnionitis: Changing our Management of Mothers and their Newborns
- Emerging Infectious Diseases Update
- Cystic Fibrosis: Recent Advances in Disease-Specific Therapies
- Parasitic Infections

Course Registration

Advance registration is required and should be received by August 18, 2017. All registration received by this date will be confirmed in writing.

The registration fees are as follows -

\$360 for physicians, \$300 for nurses and allied health professionals, and \$125 for residents and students. This fee includes all course material, refreshments and meals as noted on the schedule. **Registration is limited and will be honored in the order of the date received.**

Register
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The program will be held at the Atlantic Sands Hotel and Conference Center, on the Boardwalk in Rehoboth Beach, Delaware. The hotel offers an oceanfront pool, fitness room, spa services, restaurant/lounge and complimentary on-site parking for guests staying at the hotel. Please visit the website for more information on the hotel at www.atlanticsandshotel.com. Rehoboth Beach is a family-oriented shore resort, with lots of activities, including water sports, fun rides for the kids, shopping and some of the finest dining in Delaware.

Accreditation

This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of Nemours and Christiana Care Health System.

Nemours is accredited by the ACCME to provide continuing medical education for physicians. Nemours designates this live activity for a maximum of **14.25 AMA PRA Category 1 Credits™**. Physicians should only claim the credit commensurate with the extent of their participation in this activity.

This activity has also been submitted to the Delaware Academy of Family Physicians for approval to award 14.25 Prescribed credits.

For more detailed conference information and to register, please go to PedsUniversity.org.

If you have any questions about the conference, or registration, please contact Karen Supplee, (302) 651-6758, or karen.supplee@nemours.org.



Development and Deployment of Community Health Workers in Delaware

Establishing a Certification Program and Reimbursement Mechanism

JUNE 2017



**HEALTH MANAGEMENT ASSOCIATES
COMMUNITY STRATEGIES**

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Executive Summary

Delaware aspires to be one of the five healthiest states in the nation. It is engaged in the implementation of the Delaware State Health Care Innovation Plan, a robust, innovative strategy to achieve this goal. A key element of the state plan is to improve population health and to deploy a new workforce – Community Health Workers – to aid in the initiative.

Community Health Workers (CHWs) help improve population health by addressing the non-clinical determinants of health. As health care transformation efforts evolve throughout Delaware, provider groups, health systems, federally qualified health centers, and others are redesigning their health care workforce to emphasize prevention and primary care, while also distributing the responsibility for quality care among the qualified members of care delivery teams.

Cultivating new entry-level jobs in the health sector, like CHWs, and nurturing their career development, is an evidenced based, effective strategy for promoting prevention and better management of chronic conditions. A concerted investment in the development and broad deployment of CHWs in the workforce promises to help improve care for Delawareans and to lower costs by addressing social determinants of health that adversely affect health status, outcomes and the cost of care. Furthermore, place-based community engagement efforts that focus on meaningful employment with livable wages and the opportunity for advancement are likely to improve the living conditions within communities that contribute to persistent poverty and ill health. Concurrently, across multiple levels, it will help the state achieve its short-term and long-term economic development, workforce development, and population health goals while lessening socioeconomic and racial or ethnic inequities in health.

Stakeholders across public/private sectors are seeking to elevate the role of CHWs in Delaware and integrate CHWs as valued members of the community and health care delivery teams. The Delaware Center for Health Innovation, in partnership with the Department of Health and Social Services' Division of Public Health (DHSS/DPH), is helping to lead this effort. The Delaware Center for Health Innovation (DCHI) is a non-profit organization that collaborates with public/private partners and stakeholders to guide implementation of Delaware's State Health Innovation Plan. The DCHI Healthy Neighborhoods Committee and Workforce and Education Committee with the DPH provided oversight and guidance to a CHW Subcommittee that was charged with developing recommendations to integrate CHWs into Delaware's health professions' workforce in a systematic and sustainable way.

The CHW Subcommittee's recommendations are summarized below:

1. Establish a Community Health Worker (CHW) Certification Program

The State of Delaware should establish a voluntary CHW Certification Program that provides approved training to meet established competencies to fulfill the role and responsibilities of the professional CHW. Certification should be required for CHWs working under the supervision of a licensed, Medicaid-enrolled health care provider to allow for Medicaid reimbursement of CHW services. The approved training should be available to any/all prospective and current CHWs to further build competencies regardless of the setting of practice or intention to bill a third-party payer. The proposed certification should be voluntary, but required for those who work under the supervision of/or in concert with a licensed, Medicaid-enrolled health care provider for whom reimbursement is desired.

2. Establish a CHW Certification Board

The Certification Board (the Board) should reside within an established public agency, with the authority and capacity to guide and to sustain administration of the CHW program, such as the Delaware Health Care Commission in partnership with the Delaware Center for Health Innovation (DCHI), which should serve as a "bridge" between the board and the community. The Board should oversee functions related to the development and administration of a Community Health Worker Certification Program that is free of unnecessary barriers for the CHW workforce.

Board membership should include representatives of key public/private entities, organizations with expertise and commitment to the goals of improving population health, entities that provide CHW training or employ CHWs, community-based organizations, CHWs, and representatives of consumer health care groups.

The Board should have multiple responsibilities including, but not limited to, approving CHW training program/s, certifying and maintaining a registry of certified CHWs, and establishing a process to address grievances.

3. Establish a Curriculum Development Committee

The Board should establish and oversee a Curriculum Development Committee which should develop a curriculum that should serve as the basis of the overall CHW training program.

4. Establish Two Entry Points for Training

- For high school students as part of the Delaware Department of Education's Pathways to Prosperity program
- For current or prospective CHWs who are not high school students.

5. Develop financing mechanisms

Financing mechanisms should be developed to support the establishment of the Community Health Worker certification program and sustain the ongoing recruitment and deployment of Community Health Workers in clinical or community settings.

6. Further Considerations

- The Delaware Center for Health Innovation and the Division of Public Health should use “hot spotting” to identify neighborhoods to deploy Community Health Workers
- Common metrics should be collected by all organizations who employ CHWs to help track outcomes. (Refer to Appendix A: Metrics from C3 Project.)

Introduction

With more than \$1 billion of public and private dollars invested, Delaware is committed to transforming its health care delivery system to improve health outcomes, improve health care quality, enhance the provider and patient experience, and reduce costs. A group of dedicated health care leaders researched and explored ways to incorporate Community Health Workers as part of the solution. This group of leaders engaged in dialogue and came to some agreements on how best to utilize non-clinical personnel to address social determinants of health. These social determinants include basic needs to live healthier lifestyles, such as quality housing, access to healthy foods, and transportation resources. (Figure 1)

This report includes specific recommendations to Delaware for next steps needed in the development of a Community Health Workers Certification Program.

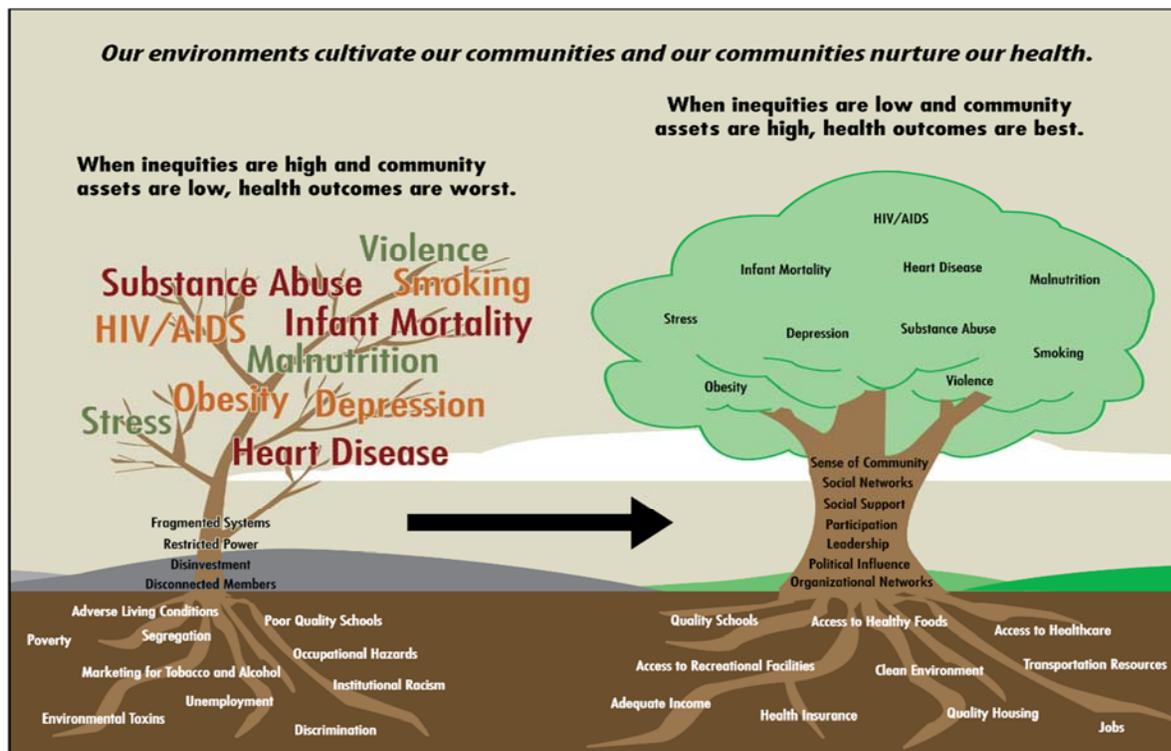
While some institutions already employ CHWs, there is, no sustainable system for training, deploying, and paying for CHWs. In 2014, during the CHW Forum on Improving Health and Quality of Life for Delawareans, it was recognized that Delaware needs to create a system that is more person-centered, team-based, coordinated, and integrated. Such a system should require a broader, more diverse workforce that focuses on prevention and wellness. The interdisciplinary teams of practitioners and health policy experts recognized the need to establish statewide infrastructure for standardized training and continuing education, credentialing, and financial sustainability for Community Health Workers.¹

In 2016, DCHI convened a CHW Subcommittee work group to research and study how to create infrastructure to support the development and deployment of CHWs, and

¹ Community Health Workers: Improving the Health and Quality of Life for Delawareans Forum Summary, April 2014

engaged Health Management Associates to assist with the project. Refer to Appendix B: CHW Subcommittee Roster for the full membership listing.

Figure 1. Health inequities in our communities.



Source: *Promoting Health Equity: A Resource to Help Communities Address Social Determinants of Health*, CDC

The CHW Subcommittee convened its first meeting in January 2017, and it was followed by six monthly meetings. The CHW Subcommittee met to review research, solicit input from stakeholders, and to develop strategies for advancing the role of Community Health Workers in Delaware. They agreed on key elements and recommendations necessary to advance policy and systemic changes toward this end. The recommendations are described on pages 10 to 17 of this report.

Background on Community Health Workers

Recent evidence suggests the effectiveness of CHW programs in improving health outcomes and additional related issues such as improved care delivery (e.g. reduced wait-time for care or appropriate use of provider services, including reduction in emergency department visits); patient knowledge and behavior (e.g. adherence to medication regimen); and sociocultural change (e.g. reduction in social stigma related to

disease).² A recent literature review published by the Minnesota Department of Health closely examined the current evidence of CHW effectiveness and quality of care.³

Health outcomes improved by CHW programs include:

- Increased cancer screening
- Case management of malaria and pneumonia
- Malaria treatment
- Diabetes management
- Reduced cardiovascular risk
- Asthma management
- Medication adherence
- Post-hospital outcomes improvement

Other health outcomes for which CHW programs demonstrate some, but not yet definitive, improvement include:

- Mental health
- Pediatric asthma
- Maternal and child health
- HIV/AIDS
- Hypertension
- Diabetes

Many health and hospital systems, health plans, and community health centers have successfully deployed CHWs to promote health among low-income communities and reduce health disparities.⁴ Cost analyses found that integrating CHWs was associated with reduced emergency department visits, reduced hospitalizations, fewer hospital readmissions, and reduced nursing home placement.⁵ Refer to Appendix C: Community Health Worker Return on Investment for further details.

² <http://www.chwcentral.org/role-and-effectiveness-community-health-workers-among-underserved-us-populations>

³ Minnesota Department of Health “Community Health Workers: A Review of the Literature”
<http://www.health.state.mn.us/divs/orhpc/workforce/emerging/chw/chwlit2016.pdf>

⁴ Services UDoHaH. Community Health Worker National Workforce Study. 2007: 1-269.

⁵ Effects of Community-Based Health Worker Interventions to Improve Chronic Disease Management and Care Among Vulnerable Populations: A Systematic Review, April 2016, Vol 106, No. 4 AJPH Research

Figure 2. Returns on Investment.



Source: Commonwealth Fund: Transforming Care: Reporting on Health System Improvement; Dec. 2015

Are CHWs Part of Delaware’s Health Care System Now?

Community Health Workers (CHWs) can help Delaware achieve health care transformation goals by serving as a link between delivery systems – medical, public health and social service – and the community. As trusted members of the community, CHWs provide culturally and linguistically sensitive and appropriate services. With the right resources, they can work with clients to address social determinants of health to achieve better health outcomes and raise health equity. The CHW subcommittee researched, discussed, drafted, and adopted a definition, scope of practice, and core competencies for CHWs in Delaware. Refer to Appendix D: Adopted Definition, Scope of Practice, and Core Competencies and Appendices F, G, H, and I for state profiles.

Several institutions and organizations in Delaware employ CHWs today, but their presence is not always continuous or sustainable. These institutions see value in integrating CHWs, but the services CHWs provide are not reimbursable.

Providers using CHWs

During the CHW Subcommittee March meeting, three CHWs employed by Christiana Health Care System; La Red Health Center, a Federally Qualified Health Center; and Beebe Healthcare, presented and discussed their specific roles in Delaware. Although their roles varied, the CHWs served to link the delivery system to the community and promote health. Examples of current activities underway in Delaware follow.

Christiana Health Care System

Christiana Care's Health Ambassador Program is funded by DPH through the federal Maternal, Infant and Early Childhood Home Visiting (MIECHV) Program. Due to funding constraints, the Health Ambassador Program has decreased CHW positions from five to two. The program sponsors a full range of activities, which are described as "completely grassroots." These include educational sessions at churches, community centers, child care centers, state services centers, and health care facilities on topics such as safe sleeping, breastfeeding, life planning, and birth control. A "community baby shower" is an example of an event held for the community twice a year. It includes educational activities, games, food, and "giveaways" of cribs, car seats, etc. Through the program's education and referral resources (e.g., 2-1-1), the staff found that many community members required hands-on support for successful linkages with health and other services to meet their basic needs.

La Red Health Center

La Red Health Center is a Federally Qualified Health Center (FQHC) in Sussex County, Delaware, with three clinical sites. A Community Health Worker who has worked with La Red's "Promotora" program since 2001 described to the CHW Subcommittee that there are 11 outreach workers: two health ambassadors, six promotores, and three additional outreach workers whose efforts are specifically targeted to addressing immunizations, homelessness, and STD/HIV. "Promotores de Salud" are traditional CHWs predominantly serving the Latino community both in Latin America and the United States. La Red receives funding from the DPH for the Health Ambassador Program; the other staff are funded through the FQHC's operating budget. La Red has not billed insurance for CHW work yet, but currently is engaged in conversation with a health insurer. La Red's CHW stated that a state credentialing program would give the CHWs additional credibility with clinical providers and with community based organizations. It would create a standard for training, competency, and professionalism.

La Red leadership stated that "Promotores de Salud" is a **cornerstone** of their practice. They noted that specialty offices won't see La Red's patients unless there is a CHW to provide translation services.

Beebe Healthcare

Beebe Healthcare's population health model emphasizes social determinants that play a significant role in health outcomes. CHWs, who function as care coordinators, are assigned to a designated group of primary care providers/practices. They also work with patients who do not have their own primary care providers, bringing them to the advanced care clinic for follow up. They contact patients by phone when they are released from the hospital, review diagnoses, verify their medications, and ensure follow up. They identify and address errors, misunderstandings, access issues, and unmet patient needs that may have occurred from discharge to home. The CHW keeps in touch with patients and helps to ensure smooth transitions of care.

Note: Care coordination and case management services are closely connected but for clarification, we include the following definitions. Care Coordination seeks to reduce fragmentation and improve health care delivery through better coordination.⁶ Case management is a process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost-effective outcomes.⁷

Health Plans Employing Community Health Workers

At the April CHW Subcommittee meeting, senior level representatives from United Healthcare Community Plan of Delaware and Highmark Delaware presented their prospective plans to hire and incorporate CHWs. Both health plans are expecting the demand for CHWs to increase. The specific health plans also described their CHW projects to date, as summarized below:

United HealthCare Community Plan of Delaware

United HealthCare has employed CHWs in Delaware since 2015 as one approach to achieve the "Triple Aim" with the Medicaid population. The Triple Aim is a framework developed by the Institute for Healthcare Improvement that describes an approach to optimize health system performance that simultaneously aims to improve the patient experience of care (including quality and satisfaction), improve the health of populations, and reduce the per capital cost of healthcare. The relationship between CHWs and beneficiaries is important since many beneficiaries suffer from multiple health care issues and need help addressing social determinants. CHWs come from

⁶ <http://jamanetwork.com/journals/jama/fullarticle/183370>

⁷ <http://www.cmsa.org/Home/CMSA/WhatisaCaseManager/tabid/224/Default.aspx>

the neighborhoods in which their members live and are familiar with the locality and the culture. United HealthCare employs seven CHWs in Delaware, 124 in the Northeast region, and over 350 nationally.

CHWs help members overcome barriers to care and connect with their provider of choice. They also advocate and help patients navigate the health care system. United notes outcomes such as reduction of emergency department utilization and unwarranted inpatient admissions.

Highmark Delaware

Highmark currently conducts complex case management via telephone, but is planning to utilize CHWs and social workers in the near future. In both commercial and Medicaid plans, Highmark has a pay-for-value program in place that includes some payment for care coordination. Highmark is considering the use of CHWs to encourage members to complete health risk assessments, conduct home visits, and coordinate services.

Creating Infrastructure for a CHW Certification Program in Delaware

To recognize and promote highly qualified CHWs as a valuable resource in health care delivery redesign in Delaware, a statewide infrastructure for training and certifying Community Health Workers is needed. The CHW Subcommittee researched approaches by multiple states and created a comparison “crosswalk” of four states that were viewed to have advanced practices: Massachusetts, Minnesota, New Mexico, and Oregon. The CHW Subcommittee used their experiences as a guide to create recommendations specific for Delaware. Refer to Appendix E: Cross Walk of Community Health Worker Training Programs, and Appendices F, G, H, and I for state specific profiles.

In Delaware, there is a need to increase the supply of CHWs – and the demand and utilization of CHWs – as a mechanism to improve population health. Outreach and education to providers must include the value CHWs provide in driving and improving health outcomes and reducing costs. Delaware will need to forecast the demand for CHWs and ensure there are sufficient numbers of trained and certified CHWs in priority communities to meet the demand.

Financing

Delaware will need startup and implementation funds to create necessary infrastructure and operations for the CHW Certification Program, as well as long-term financing mechanisms that allow for payment for CHW services.

Startup and Implementation Funds

Implementation budgets need to include personnel and operating expenses. Oregon's Traditional Health Workers program has a full-time program coordinator, and a full-time health equity workforce assistant. In addition to personnel costs, they budgeted \$34,000 for board and CHW Subcommittee expenses.

Reimbursement for CHW Services

Based on a Centers for Medicare & Medicaid (CMS) rule change (revised 42 CFR 440.130(c)), Medicaid can reimburse for CHW services, if recommended by a physician or other Medicaid-enrolled licensed practitioner. This policy change is critical to CHW workforce support and sustainability.

A CMS Information Bulletin dated November 27, 2013 states: "Since 42 CFR 430.10 requires state plans to be comprehensive written statements describing the nature and scope of a state's Medicaid program and contain all information necessary for CMS to determine whether the plans can be approved to serve as the basis for federal financial participation (FFP), states must include in their State Plan Amendment a summary of practitioner qualifications for practitioners who are not physicians or licensed practitioners. The summary should include any required education, training, experience, credentialing, or registration. This approach is similar to our long-standing approach for providers and practitioners of state plan rehabilitative services. We are available to provide technical assistance to states." Thus, Delaware will need to submit a State Plan Amendment to ensure CHWs can be reimbursed.

Recommendations of the CHW Subcommittee

Community Health Workers (CHWs) are a critical part of the health care workforce and are valuable members of the health care team. They play a crucial role in helping individuals achieve and maintain better health. CHWs link community members with the health care system, improve access, and get them services they need. They also play a critical role in identifying and addressing social determinants of health that impact health outcomes. Because the work of CHWs is often grant-funded, their presence is not always continuous or sustainable. Despite the essential role CHWs play, their role

may not be well-understood or appreciated by the health care system, and they are often underutilized.

Establishing a CHW credential will help elevate the CHW role as a respected, valued professional in the health care workforce. Creating opportunities for more sustainable CHW funding should ensure continuity and that they are well-integrated within the health care system and the community. An important way to achieve CHW integration in the health care system, sustainability, and job security for CHWs is to maximize funding through third-party reimbursement, including Medicaid and other payors. A reimbursement system will require CHWs to be trained and credentialed. In addition to being qualified to have their services reimbursed, trained CHWs may be entrusted to add notes to patient health records, giving clinicians information about the overall environmental factors contributing to the social determinants of their health relative to what is needed in an effective, comprehensive treatment plan.

The CHW credential is not intended to diminish the work of already practicing CHWs regardless of title or employment status. This includes volunteers or non-traditional community workers who engage community members to promote prevention and health maintenance. For instance, CHWs who are currently providing services may encourage community members to take advantage of cancer screenings, or provide support to neighbors to help them manage conditions such as asthma, heart disease, and other chronic conditions. The CHW Subcommittee would like to ensure all CHWs, regardless of employment status or title, be embraced to practice at the level of their training, experience, and or accepted role in the community.

Between January and June 2017, the CHW Subcommittee on Community Health Workers researched other state models, solicited input from stakeholders, and discussed strategies for advancing the role of Community Health Workers in Delaware, culminating their work with the development of these recommendations that follow.

1. Establish a Community Health Worker Certification Program

The State of Delaware should establish a voluntary CHW Certification Program that provides approved training to meet established competencies to fulfill the role and responsibilities of the professional CHW. Certification should be required for CHWs working under the supervision of a licensed, Medicaid-enrolled health care provider to allow for Medicaid reimbursement of CHW services. The approved training program should be available to any/all prospective and current CHWs to further build competencies, regardless of the setting of practice or intention to bill a third-party payer. The CHW Subcommittee is recommending legislation to create the Board and the certification program. The proposed certification will be voluntary, but required

for those who work under the supervision of/or in concert with a licensed, Medicaid-enrolled health care provider for whom reimbursement is desired.

The definition of certification is as follows:

“Certification” means the successful completion of a State Department of Education approved training program and enrollment in Delaware’s CHW registry.

“Certification” is a mechanism that can assure CHWs are trained and have mastered specific competencies necessary for the proper execution of their duties. Because the scope of practice for CHWs does not include clinical duties, and the CHW practice does not pose a significant risk of harm to the public, “licensure” is not required.

2. Establish a CHW Certification Board

To successfully oversee the CHW program, the state should establish a Community Health Worker Certification Board (the Board). The Board should reside within an established public agency, with the authority and capacity to guide and to sustain administration of the CHW program, such as the Delaware Health Care Commission, within DHSS. The CHW Subcommittee recommends designating the Delaware Center for Health Innovation (DCHI) as the organization that should work with the Board as a “bridge” between the Board and the community. DCHI’s role should include aligning the demand for CHWs with the emerging supply that should enter the workforce through the new credentialing program. DCHI should promote the value and opportunity of trained CHWs in health care, public health, and social service delivery systems. The Board should oversee functions related to the development and administration of a user-friendly Community Health Worker Certification Program that is free of unnecessary barriers.

The Board, to be appointed by the governor, is intended to elevate the status of community health workers as an occupation in order to promote health equity, cost containment, quality improvement, prevention and management of chronic disease, and help address the social determinants of health that affect individuals and communities’ health and well-being.

Board membership should include:

- Representatives of key public/private agencies, including Delaware Public Health, including its Bureau of Health Equity; Delaware Health Information Network; Delaware Center for Health Innovation; Delaware Health Care Commission; hospitals, Accountable Care Organizations, and FQHCs

- Representatives of community-based organizations with expertise and commitment to the goals of improving population health, including entities that provide training, and/or who employ CHWs
- Community Health Workers
- Representatives of the health care industry who provide training and/or employ CHWs.

CHW Definition, Scope of Practice, and Core Competencies

The Board should be presented with the CHW definition, scope of practice, and set of core competencies and instructional topics, developed and agreed upon by the CHW Subcommittee (attached as Appendix D) with extensive and broad stakeholder input. The Board should adopt the Community Health Worker definition, scope of practice, and set of core competencies as the basis for standardizing the role and integration of CHWs in Delaware’s health care workforce and landscape, and for overseeing the development of a standard curriculum for initial training and continuing education and certification of CHWs.

The Board should establish an annual process to review and assess the definition, scope of practice, and set of core competencies and update or modify them as needed to ensure ongoing relevancy, value, and integration of CHWs.

Board Activities and Responsibilities

The Board should conduct activities which include:

- Establishing criteria and approving entities to provide CHW training and continuing education, and designing and maintaining a database for approved training program entities
- Establishing and implementing a process for individuals who successfully complete an approved training program to apply for CHW certification and to renew certification, and designing a process that provides easy access to continuing education units, including distance learning opportunities
- Establishing and implementing an approval process for “grandfathering” existing CHWs who have not completed an approved training program, and an approval process for CHWs who are certified in other states
- Designing and maintaining a database or registry of all certified CHWs that includes information such as date of certification, adherence to continuing education requirements, place of employment and other information relevant to an individual’s certification and employment

- Establishing fees and a process for collecting fees to support the CHW certification program
- Establishing a process for submitting and addressing grievances
- Establishing rules necessary to ensure the protection of public health and safety, per Delaware law
- Executing a public awareness campaign on the critical role CHWs play in the community and as valued members of the health care team, in collaboration with stakeholders, including but not limited to DCHI and DPH. The campaign should help the broader community understand the value of community health workers and create further acceptance and demand for their services. The campaign's focus should be two-fold:
 - To create an appreciation of the contribution Community Health Workers make in supporting family members, friends and neighbors, and to help community members understand how to find a Community Health Worker when one is needed, and
 - To communicate directly to health care providers and community service providers about the vital role community health workers play as integral members of the health care team, and how they help ensure that patients' social needs are met so they can fully benefit from the health services they receive.

3. Establish a Curriculum Development Committee

Establish a Curriculum Development Committee that should report to the Board to create a curriculum that should form the basis of the CHW training program. Membership of the Curriculum Development Committee should include state institutions of higher education, health care industry leaders, prospective employers, and CHWs. Members should include experts sensitive to the educational needs and learning styles of individuals who may not have experience or may not be comfortable in an academic environment.

The Curriculum Development Committee should consider the CHW core competencies and instructional topics adopted by the CHW Subcommittee as a starting point for their work. Refer to Appendix J for draft CHW Core Curriculum Competencies. They were created with due diligence after a careful review of others states' approved curriculum and being vetted by CHWs working in Delaware, educational professionals, providers, payors, and both the Healthy Neighborhood Committee and Clinical Committee of the Delaware Center for Health Innovation.

In addition to a core curriculum for Community Health Workers, the committee should consider ways in which the curriculum could be enhanced or extended to provide in-depth learning on specialized topics such as maternal and infant health, chronic disease management, or other specific areas. Once the committee completes its work, the Board should be responsible for obtaining approval from the Department of Education and gathering any other necessary approvals. The Curriculum Development Committee also should recommend a process for the Board to consider future additions or amendments to the curriculum or alternative curricula.

4. Establish Entry Points for CHW Training and Certification

Establish two “entry points” for individuals to obtain training that can lead to Community Health Worker certification.

- a. In collaboration with the Delaware Department of Education, the Board should develop a matriculation agreement with the Pathways Program to launch the CHW training program for high school students.
- b. In collaboration with the Department of Labor, the Board should establish a mechanism to provide access to participate in a training program that can lead to CHW certification for current CHWs and aspiring CHWs who are not high school students.

Two “entry points” are needed to ensure a viable pathway for both new entrants to the workforce and more experienced workers to obtain appropriate, sanctioned training for CHW certification. For experienced, practicing CHWs, there should be a grandfathering process to be determined by the Board.

5. Develop Financing Mechanisms

Develop financing mechanisms that can support the establishment of the Community Health Worker certification program and support Community Health Workers as members of health care teams and the community. Funding mechanisms such as the following strategies should be considered:

- a. Hospital funding to support the creation and implementation of the CHW curriculum and the CHW certification program. As part of supporting the educational process, hospitals could help fund internships or other practical experiences for aspiring CHWs. A pool of funds could also be created to help defray tuition and certification fees.

Nonprofit hospitals receive favorable tax status under the Internal Revenue Service's tax codes in acknowledgement of the "community benefit" they provide, such as free or reduced cost care and spending that promotes community health. Hospitals may also now claim what the IRS terms *community building activities* to meet the IRS' community benefit standard. These can include leadership development, training for community members, and workforce development.

- b. Maximize Medicaid funding to support the ongoing employment and advancement of Community Health Workers:
 - Establish rules to allow Medicaid to reimburse providers for services conducted by certified CHWs who are employed and supervised by a licensed Medicaid-enrolled provider or contracted plan.
 - Embed in Medicaid managed care contracts the expectation that CHWs should be deployed as part of initiatives to improve care, improve health outcomes, and reduce costs, and that Medicaid Performance Improvement Projects (PIPs) should include CHWs. Once a certification program is established, Medicaid Managed Care Organizations (MCOs) should be required to inform beneficiaries that CHWs are available. MCOs should be required to contract directly with providers who can offer the CHW service.
 - Allow Medicaid MCOs to apply the costs of CHWs to service delivery rather than administrative expenditures.
- c. Consider the role of Community Health Workers as an integral part of any new health care payment models.
 - Include the function of CHWs in new payment models to recognize reimbursement and participation as core members of care coordination teams.
 - Allocate a portion of shared savings to be used to support Community Health Workers located in the community who are addressing population health, such as cancer health ambassadors.
 - Advocate for commercial payors to adopt population-health payment models, and recognize the value of Community Health Workers in helping to improve health outcomes.
- d. Allocate state funds and/or raise private funds to support the creation and implementation of a public awareness campaign about the critical role of

Community Health Workers and how their efforts can benefit consumers and health care providers.

6. Further Considerations

- a. The Delaware Center for Health Innovation and Delaware Public Health should conduct a study, using “hot spotting” and mapping methodologies to identify Delaware localities where deployment of CHWs would be most beneficial.
- b. The Board should identify metrics that should be collected by all organizations and institutions that employ CHWs. This should help Delaware track the work of CHWs and the outcomes produced because of their efforts. Such information can help detect the need for mid-course corrections in training and program implementation, and provide information to help Delaware evaluate the program.

Appendix A: Metrics from C3 Project

Underway among many stakeholders, at individual and organizational levels, are efforts to identify key evaluation measures that demonstrate the effect of CHWs on improving health outcomes, increasing access to care, and reducing costs. The American Public Health Association's *C3 Project* (Project on Community Health Worker Policy and Practice)⁸ is housed within the University of Texas Institute for Health Policy and led by Dr. Hector Balthazar. This long-term project has the goal of defining CHW scope of practice and advancing the development of CHW policy and financing strategies, nationally.

At the University of Michigan, Dr. Edith Kieffer runs the "Common Indicators Project"⁹ which aims to create a common set of evaluation indicators and measures to capture the contributions of CHWs to successful program outcomes to improve population health and their added value to health care and human services systems. National and state organizations such as the Public Health Institute and CHW Central are also heavily involved in developing measures and metrics that can be used across CHW programs.¹⁰ However, among these groups, research is still underway and consensus has not yet been reached. Nonetheless, it is recommended that any CHW program being built and implemented today should include formative, process, and outcome evaluation components through which data can be collected systematically and longitudinally for determining programmatic effectiveness and return on investment.

⁸ <https://sph.uth.edu/research/centers/ihp/community-health-workers/>

⁹ <http://www.michwa.org/wp-content/uploads/CI-Project-Overview.pdf>

¹⁰ <http://ssw.umich.edu/offices/research/projects-grants/developing-common-community-health-worker-chw-evaluation-indicators-to-measure-and-increase-program-and-policy-impact/WEB20>

Appendix B: CHW Subcommittee Roster

NAME	ORGANIZATION	TITLE
Kathy Janvier , Co-Chair DCHI Workforce & Education Committee	Delaware Technical Community College	Vice President & Campus Director
Lolita Lopez , Co-Chair DCHI Healthy Neighborhoods Committee	Westside Family Healthcare	President & CEO
Cassandra Codes-Johnson	Division of Public Health	Associate Deputy Director
Nadinia Davis	Delaware Technical Community College	HIM Program Coordinator
Norma Everett	Nemours	Manager, Population Health
Tyrone Jones	United Way of Delaware	Chief Impact Officer
Tanner Polce	Office of the Lieutenant Governor	Policy Director
Brian Rahmer	Christiana Care Health System	Director of Community Health Engagement
Megan Williams	Beebe Medical Center	Executive Director of Population Health
SUPPORT:		
Julane Armbrister	Delaware Center for Health Innovation	Executive Director
Judith Chaconas	Division of Public Health	Director of Planning and Resources Management
Noel Duckworth	Delaware Center for Health Innovation	Healthy Neighborhoods Project Manager
Maggie Norris-Bent	Westside Family Healthcare	Community Relations and Marketing Specialists

Note: The CHW Subcommittee included membership from the Delaware Center for Health Innovation's Clinical Committee, Workforce and Education Committee and Healthy Neighborhoods Committee.

Appendix C: Community Health Worker Return on Investment

Historically, financial sustainability has been the single greatest barrier to CHW programs in the United States, as stated in a 2016 Health Affairs Internet blog titled, “How-to Build Sustainable Community Health Programs in the United States.” CHW program funding has been limited and sporadic, often coming from multiple public and private funding streams, including time-limited grants, state and local general funds, Section 330¹¹ health center grants, and Medicaid.¹² Initially, many planners of CHW programs did not take into account programmatic components such as operational costs for training, recruitment, supplies, monitoring and evaluation, etc., and this impeded the success and sustainability of many programs.¹³

Documenting return on investment or the cost effectiveness of CHW programs has been a key focus area for advocates of CHWs since the 1980s.¹⁴ Making the business case that implementing a CHW program should yield savings or return on investment, for example, by lowering emergency department utilization rates or achieving shorter hospital stays, is key to securing investments and making programs sustainable.

Recent studies of CHW program, three of which are detailed below, describe successful returns on investment and improved health outcomes.

1. **Access to Primary Care and Hospital Readmissions.** The PENN Center for Community Health Workers (PCCHW) IMPaCT (Individualized Management for Patient-Centered Targets) Model offered individualize support to high-risk patients to help them achieve their specific health goals and to establish primary care. CHWs guide patients through stages to set goals, provide ongoing support; and connect to primary care practices. CHWs meet patients on the day of hospital discharge and assist them in setting goals for a successful recovery. They work directly with patients for two weeks. The intervention improved patients’ *access to primary care* and lowered rates of *preventable hospitalizations*. The return on investment was \$1.80 for every \$1 spent on the program.¹⁵

¹¹ Health Resources and Service Administration, Section 330 of the Public Service Act is a federal funding program for health centers located in medically underserved areas or serve medically underserved populations and provide primary and preventive health services regardless of a patient’s ability to pay.

¹² Minnesota Department of Health “Community Health Workers: A Review of the Literature” <http://www.health.state.mn.us/divs/orhpc/workforce/emerging/chw/chwlit2016.pdf> and National Health Care for the Homeless Council, “Community Health Workers: Financing & Administration” 2011. <https://www.nhchc.org/wp-content/uploads/2011/10/CHW-Policy-Brief.pdf>

¹³ Perry, Henry, Franciso Sierra-Esteban, and Peter Berman. “Chapter 5: Financing Large-Scale Community Health Worker Programs,” n.d.

¹⁴ Kangovi S, Grande D, Trinh-shevvin C. “From rhetoric to reality—community health workers in post-reform U.S. health care” 2015. *New England Journal of Medicine*. June 11 2015 VI. 372, No. 24: 2277-9.

¹⁵ Morgan AU; Grande DT; Carter T, et. Al. “Penn Center for Community Health Workers: Step by Step Approach to Sustain and Evidence-based Community Health Worker Intervention at an Academic Medical Center.” *AJPH* November 2016, VI 106 (11): 1958-1960).

2. **Reduced Inpatient Readmissions, Weight Loss, Increased Activity, and Improved Blood Pressure via Self-management of Chronic Conditions (Diabetes, Asthma, and Chronic Obstructive Pulmonary Disease).** Spectrum Health, a 12-hospital health care system in Michigan, implemented a year-long core-curriculum taught by CHWs on self-management for patients with chronic conditions. Cardiac and diabetes patients in receipt of at least one home visit a month had fewer readmissions, lost weight, increased activity levels, improved blood pressure, and had fewer dental visits than before. Inpatient readmission charges for diabetes patients reduced by 39 percent and inpatient readmission costs for heart failure patients fell by 9.5 percent, while readmission costs for patients with both conditions decreased more than 14 percent. Overall ED use fell, resulting in cost savings of more than 29 percent.¹⁶
3. **Increased Primary and Specialty Care Visits and Decreased Urgent Care, Inpatient, and Outpatient Behavioral Health Care Utilization.** The Denver Health Community Voices CHW program in a public safety net setting provided 12 CHWs to conduct outreach with underserved and special populations. CHW outreach included community-based screening and health education, assistance with enrollment in publicly funded health plans, referrals, system navigation, and care management. CHW intervention resulted in increased primary care and medical specialty visits and decreased urgent care, behavioral health, and inpatient visits. Total charges decreased by \$300,000 and the return on investment of the total program was \$2.28 saved for every \$1 invested in CHW program.¹⁷

However, despite the mounting evidence that CHW programs are cost effective, this report acknowledges the lingering consensus among stakeholders that further empirical evidence is needed to bolster the argument for CHWs. Some stakeholders are encouraging further studies to demonstrate how specific CHW models create value, for whom that value accrues (i.e. the health plan, the hospital, the patient, etc.), and how that value could translate into opportunities for investment.¹⁸

¹⁶ Larson, Laurie. "Doing Their Homework: Community Health Worker Program Records Quantifiable Gains for Patients, System." *Trustee* June 2016 vl 69 (6): 10-14.

¹⁷ Whitley EM, Everhart RM, and Wright RA. "Measuring Return on Investment of Outreach by Community Health Workers." *Journal of health Care for the Poor and Underserved* 2006 vl. 17: 6-15.

¹⁸ <http://healthaffairs.org/blog/2016/12/20/how-to-build-sustainable-community-health-programs-in-the-united-states/>

Appendix D: Adopted Delaware Definition, Scope of Practice, and Core Competencies

DEFINITION

A Community Health Worker (CHW) is a valued part of the health team who serves as a frontline liaison, guiding individuals and families through the health, social, and community services systems to foster health and well-being. As a trusted member of the community, the CHW is sensitive to the demographics and experiences of the community, and provides culturally and linguistically competent and appropriate services. The CHW has the skills and capacity to address the social determinants of health to achieve better health outcomes and health equity for the populations and communities served.

SCOPE OF PRACTICE

Community Health Workers build individual and community capacity by:

1. Serving as a link between communities and health/social service agencies
2. Administering screenings to identify needs associated with the social determinants of health and facilitating access and information to services and resources to address such needs
3. Promoting health and wellness within the community
4. Providing culturally competent education and service delivery, as well as service delivery informed by an understanding of trauma and its effects on health and well-being
5. Enhancing community members' ability to effectively communicate with health care providers
6. Connecting community members to interpretation and medical translation services
7. Conducting outreach and organizing health education
8. Providing information counseling and social support on health behaviors

CORE COMPETENCIES (DOMAINS)

Community Health Workers have the following core competencies:

1. Community Health Outreach and Advocacy
2. Effective, Culturally Competent Communication Skills, including:
 - Interpersonal skills
 - Documentation Skills (and Computer Literacy)
3. Service Coordination, Triage, and Safety
4. Health Coaching/Education to Promote Healthy Behavior Change
5. Time and Stress Management
6. Community Knowledge and Assessment

Appendix E: Cross Walk of Community Health Worker Training Programs

	Oregon	Minnesota	Massachusetts	New Mexico	Delaware
<p>State Certification Programs for CHWs</p> <p>The Oregon Health Authority (OHA) certifies Traditional Health Workers (THWs). Certificate required to enroll as provider to receive Medicaid reimbursement. THW types:</p> <p>Community Health Workers - linkage to health care.</p> <p>Peer Support Specialists - support and assistance to consumers with addictions and mental health needs.</p> <p>Peer Wellness Specialists - support and assistance to consumers with physical and mental health needs.</p> <p>Personal Health Navigators - care coordination for members from within the health system.</p> <p>Birth Doulas - companionship and non-medical support to women and families throughout childbirth and post-partum.</p>	<p>Minnesota Department of Human Services (DHS) requires CHW certification for billing for CHW services covered under Minnesota Health Care Programs (MHCP) and Medicaid.</p> <p>-CHW certification is not required for employment.</p> <p>-Certification is provided by the approved training program once the applicant has completed the CHW curriculum.</p>	<p>Massachusetts Department of Health and Human Services' Department of Public Health established a CHW certification Board.</p> <p>-The Board has drafted guidelines for voluntary CHW certification and training program approval; will be ready for public comment in mid-2017.¹⁹</p>	<p>The New Mexico Department of Health's Office of Community Health Workers (OCHWs) administers a voluntary, statewide certification program for CHWs.</p>	<p>Certificate program that recognizes competencies and moves towards certification (gatekeeping). Create a ladder first with basic level of knowledge and build opportunities to advance.</p> <p>Long-term Goal: Certification; Department of Health and Human Services (DHHS) is recommended as the approval body to approve CHW certification programs.</p>	
<p>CHW Eligibility</p> <p>-At least 18 years old</p> <p>-Not be listed on Medicaid provider exclusion list</p> <p>-Successful completion of all training requirements for certification</p>	<p>-HS diploma or GED</p>	<p>-18 and above</p> <p>- "Good moral character."</p>	<p>-At least 18 years old</p> <p>-HS diploma or GED</p> <p>-Certificate of completion from a Department of Health CHW Certification Training Program or other</p>	<p>Two entry points:</p> <p>1. High School Student (Dept of Ed agreement w/Pathways Program to launch CHW training program.)</p>	

¹⁹ London, K; Carey, M.; and Kate Russell. "Community Health Worker Certification Requirements by State." Brief by the Connecticut Health Foundation. Feb 2016.

-Submit all required documentation and a completed application
 -Pass a criminal background check

NM endorsed training program.
 -Pass a criminal background check.

2. At least 18 years old w/ or w/out GED, passing a criminal background check – state and federal. (Dept. of Labor establishes mechanisms.)
 Both pathways: not being on Medicaid provided exclusion list

Competencies

Core Competencies	Core Competencies	Core Competencies	Core Competencies	Core Competencies
<ol style="list-style-type: none"> Demonstration of basic outreach and mobilization skills Demonstration of basic community and cultural liaison skills Demonstration of basic case management, care coordination and system navigation skills Demonstration of basic health promotion and coaching skills 	Core Competencies <ol style="list-style-type: none"> Roles, Advocacy and Outreach Organization and Resources Teaching and Capacity Building Legal and Ethical Responsibilities Coordination, Documentation and Reporting Communication and Cultural Competency Other Non-Core Competencies <ol style="list-style-type: none"> Health Promotion Competencies Practice Competencies - Internship 	Core Competencies <ol style="list-style-type: none"> Outreach Methods and Strategies Individual and Community Assessment Effective Communication Cultural Responsiveness and Mediation Education to Promote Healthy Behavior Change Care Coordination and System Navigation Use of Public Health Concepts and Approaches Advocacy and Community Capacity Building Documentation Professional Skills and Conduct 	Core Competencies <ol style="list-style-type: none"> The CHW Profession Effective Communication Interpersonal skills Health Coaching Service Coordination Advocacy Technical Teaching Community Health Outreach Community Knowledge & Assessment Other Non-Core Competencies <ol style="list-style-type: none"> Clinical Support Skills are optional for those who desire to enhance their skills or whose jobs require it. 	Core Competencies: <ol style="list-style-type: none"> Community Health Outreach and Advocacy Effective, Culturally Competent Communication Skills, including: Interpersonal skills Documentation Skills (and Computer Literacy) Service Coordination, Triage, and Safety Health Coaching/Education to Promote Healthy Behavior Change Time and Stress Management Community Knowledge and Assessment

Curriculum

-Oregon's curriculum consists of a set of roles, each with a definition and detailed competencies.

-Additional required curriculum is detailed for specific worker types, particular practices settings, and jobs.

-Minnesota's curriculum consists of core competencies with associated learning objectives.

-The curriculum features a 2-credit internship that enables CHW students to apply and integrate classroom instruction.

Massachusetts' curriculum consists of core competencies with a set of associated learning objectives.

Standardization of curriculum, based on core competencies, is currently in development.

Curriculum would include core competencies and include coursework and a practicum.

Curriculum Link:
<https://www.oregon.gov/oha/oei/reports/The%20Role%20of%20Non-Traditional%20Health%20Workers%20in%20Oregon's%20Health%20Care%20System.pdf>

Curriculum Link:
<http://mnchwalliance.org/wp-content/uploads/2012/12/Minn-esota-CHW-Curriculum-Outline-Updated-Feb-2015.pdf>

Curriculum Link:
<http://www.mass.gov/eohhs/gov/departments/dph/programs/hcq/dhpl/community-health-workers.html>

Curriculum Link:
Not yet available

Initial Training Requirements

80 contact hours from approved training program addressing core curriculum, and any additional curriculum topics specific to type of worker.

14 credit certificate program (equates to approximately 220 contact hours if use typical 15 to 16 hours/credit.)

Must use MN standardized curriculum offered by Minnesota State Colleges and Universities, as well as other entities

100 contact hours from OCHW-endorsed curriculum available through community colleges, universities, agencies, and other community based organizations.

Minimum of 80 contact hours (equivalent to five credits) for core curriculum. [60 to 74 credits for Associates Degree.]
May need to do more research to determine how many hours needed to meet competencies.

Continuing Education Requirements

20 hours of Authority approved continuing education during every three year renewal period.

15 hours continuing education every two years.

30 hours of CEUs as approved by the Department of Health every two years.

Grandfathering Experienced CHW

Yes.
-Verifiable evidence working/volunteering as CHW

Yes.
-At least five years of supervised experience with an enrolled

Yes.
-Credentialed pathway for individuals with 4,000

Yes.
-Verification by a current or former supervisor of

Yes.
-Grandfather for limited period of time

for at least 3000 hours between Jan 1, 2008 – June 30, 2016 -At least one letter of recommendation from relevant employer.	physician, registered nurse, advanced practice registered nurse, mental health professional, or dentist, or work under the supervision of a certified public health nurse operating under the direct authority of an enrolled unit of government.	hours relevant work experience. -“Work only” pathway will be phased out three years after the state certification program begins.	proficiency in the core competencies. -Two letters of reference on agency/program letterhead. -Applicants must provide formal, verifiable documentation to support requirements. -2,000 clock hours of formal CHW work and/or volunteer CHW experience within the scope of work and core competency field. -Grandfathering application and background check.
No. -Oregon Health Authority State certification and registration is free once training requirements are met. -CHW pays the cost of the training program.	No. -CHW pays cost of the training program.	Yes. -There should be a fee for certification. The amount is not currently available. -CHW pays cost of the training program.	Yes. -\$45 fee is required for initial certification as Generalist, and \$44 for a background check for approved applicants. -For those applying for a Specialty Area, an additional \$10 per Specialty Area is charged. -CHW pays cost of the training program.
Yes. State removes CHWs from registry following certification expiration w/out renewal. -Community organizations and colleges apply to become an OHA-approved THW training program.	No. No roster outside of Medicaid enrolled CHWs MnSCU (Minnesota State Colleges and Universities) licenses the use of their CHW curriculum. However, they are working on an agreement with	Not applicable at this time. There are several training programs currently offering CHW coursework; these should need to be approved by the State in	Yes. Plan to develop CHW registry; CHWs should need to consent to be included in registry. -Training programs submit an application for endorsement. -Can use NMDOH/OCHW Certification Training

CHW Fees for Certification

State Registry of CHWs

Training Program Approval: Application and

Renewal Process

-Training organizations are required to submit a training program application and CEU training application with curriculum detail, and attest to meeting particular requirements, including validation of student curriculum completion.
 -Once approved, OHA includes the organization in their on-line list of training sites.
 -Training programs are required to renew their application every three years.

the CHW Alliance to take on that role in the future.

order for students to qualify for state certification as CHWs.

Program or other training program that focuses on state-defined competencies.

State Registry of CHW Training Programs

A list of training programs is maintained on the OHA website that indicates training programs for which OHA approval has been granted, approval and expiration dates, contact information. There are currently eight approved training programs statewide.

DHS Provider enrollment maintains a list of eligible programs.

A list of training programs is currently on State website; these are pending review and approval.

There is only one State-endorsed program at this time. State plans to make the list of endorsed programs available.
 Yes.
 The state should maintain a registry of current, approved training programs.

State Contact Information

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Appendix F: Profile of Massachusetts' CHW Program

Background

Overall program webpage: www.mass.gov/dph/communityhealthworkers. This home page lists hyperlinks to other resources on the web:

- [CHW Definitions](#)
- [CHW Training Resources](#)
- [CHW Certification](#)
- [DPH and Other Massachusetts CHW Resources and Support](#)
- [National and Selected Resources from Other States](#)
- [Policy and Financing](#)
- [Evidence and Research](#)
- [CHWs and Health Reform](#)
- [CHW Organizations](#)

The Massachusetts Association of Community Health Workers (MACHW) site is here: <http://www.machw.org/>

The Massachusetts Department of Health (DPH) promotes the engagement of CHWs to its partners and grantees, and its webpage has hyperlinked resources for **Community and Healthcare Linages Community of Practice**: <http://www.mass.gov/eohhs/gov/departments/dph/programs/community-health/prevention-andwellness/comm-health-wkrs/dph-and-other-massachusetts-chw-resources-and-support.html>

CHW's Standards/Training/Curriculum

The **Board of Certification of Community Health Workers** establishes standards for the education and training of community health workers and community health worker trainers, standards for the education and training program curricula for community health workers, and requirements for community health worker certification and renewal of certification. The Board is comprised of 11 seats, appointed by the governor, four of which are to be occupied by CHWS.

- <http://www.mass.gov/eohhs/gov/departments/dph/programs/hcq/dhpl/community-healthworkers/about/about-the-board.html>

CHW Certification is available through the Massachusetts Department of Public Health Division of Health Professions Licensure. There is a fee, and certification is valid for two years and can be renewed. Must complete 80 hours classroom training and 15 hours of continuing education credits every two years.

Core competencies and curriculum learning objectives, described in full here:

<http://www.mass.gov/eohhs/gov/departments/dph/programs/hcq/dhpl/community-healthworkers/ma-board-of-certification-of-community-health-workers.html>, include:

- Outreach Methods and Strategies
- Individual and Community Assessment
- Effective Communication
- Culturally-based communication and care
- Health Education for Behavior Change
- Professional Skills and Conduct
- Support, Advocacy and Coordination of Care for Clients
- Application of Public Health Concepts and Approaches
- Advocacy and Community Building
- Documentation

The Massachusetts' Health and Human Services site hosts a webpage with links to **CHW Training Resources**:

<http://www.mass.gov/eohhs/gov/departments/dph/programs/communityhealth/prevention-and-wellness/comm-health-wkrs/chw-training-resources.html>

Legislation and Rules

The Massachusetts DPH Office of CHWs was established in 2009 in response to one of a series of recommendations in a **report** to the legislature (<http://www.mass.gov/eohhs/docs/dph/com-health/com-healthworkers/legislature-report.pdf>) mandated by a provision of the 2006 Massachusetts health care reform law (<https://malegislature.gov/Laws/SessionLaws/Acts/2006/Chapter58>, Section 110). It sits within the Division of Prevention and Wellness. The office helps to coordinate the workforce development activities, listed above. In addition, it supports the work of the Division in promoting CHWs in chronic disease prevention and management.

The **Board of Certification of Community Health Workers** was established through an act of the legislature, Chapter 322 of the Acts of 2010, with an effective date of January 1, 2012. It was created because of state health care reform and is intended to help integrate community health workers into the health care and public health systems in order to promote health equity and for cost containment, quality improvement, and management and prevention of chronic disease. The Board should establish standards for the education and training of community health workers and community health worker trainers, standards for the education and training program curricula for community health workers, and requirements for community health worker certification and renewal of certification.

<http://www.mass.gov/eohhs/gov/departments/dph/programs/hcq/dhpl/community-healthworkers/about/about-the-board.html>

Funding/Medicaid/State Plan Amendment

Several funding streams and state strategies exist for payment and reimbursement of CHWS. They include the Dual Eligibles Program (One Care), the 1115 Waiver, or the Blue Cross Blue Shield of Massachusetts Foundation. These are listed and hyperlinked on the webpage here:

- <http://www.mass.gov/eohhs/gov/departments/dph/programs/community-health/preventionand-wellness/comm-health-wkrs/dph-and-other-massachusetts-chw-resources-and-support.html>

Further, the Massachusetts' Division of Public Health Prevention and Wellness Trust Fund was established 2012 with over \$60 million to allocate toward chronic condition prevention programs, and each partnership includes CHWs in some capacity.

Examples of CHWs working in Massachusetts:

The Massachusetts Association of CHWs (MACHW) homepage lists <http://www.machw.org/> resources on workforce development, including topics of certification policy, and posts recent job openings:

- Workforce Development
http://www.machw.org/index.php?option=com_content&view=article&id=31&Itemid=103
- Training
http://www.machw.org/index.php?option=com_content&view=article&id=32&Itemid=146
- Policy
http://www.machw.org/index.php?option=com_content&view=article&id=48&Itemid=147
- Job openings
http://www.machw.org/index.php?option=com_content&view=article&id=45&Itemid=124

Appendix G: Profile of Minnesota CHW Program

Background

Minnesota used the APHA definition of CHW. Minnesota uses the terms and definitions:

- **Community Health Workers (CHWs):** Community-based health care providers who provide health promotion and disease prevention services in their communities and have completed an Indian Health Service (IHS) funded, tribally contracted or granted and directed program of training.
- **Community Health Representatives (CHRs):** A health worker who is a trusted member of or has an unusually close understanding of the community served, which enables the person to provide information about health issues that affect the community and link individuals with the health and social services they need to achieve wellness.

Overall program webpages

Minnesota (MN) Department of Human Services' webpage:

http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs16_140357

MN Department of Health webpage has a CHW Toolkit with ample links to CWH material:

<http://www.health.state.mn.us/divs/orhpc/workforce/emerging/chw/index.html>

CHW Training/Standards/Curriculum

CHWs must obtain certification from Minnesota State Colleges and Universities System with an approved community health worker curriculum, and then they can enroll to be deemed an "Eligible Provider." An eligible enrolled billing provider must bill for services for the CHW to receive payment.

Enrollment information, application forms, and a list of Eligible Billing Providers are listed and linked on the state CHW webpage:

http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs16_140357

Curriculum

The Minnesota Community Health Worker curriculum is based on the core competencies identified in Minnesota's CHW "Scope of Practice." The curriculum also incorporates health promotion competencies as an introduction to a broad range of individual, family, and population health needs. The internship is the centerpiece of the curriculum's practice competencies. It enables CHW students to fully apply and integrate what they have learned in the program to ensure an effective transition to the CHW role.

Curriculum Overview: <http://mnchwalliance.org/wp-content/uploads/2012/12/Minnesota-CHW-Curriculum-Outline-Updated-Feb-2015.pdf>

Core Competencies: <http://www.health.state.mn.us/divs/orhpc/workforce/emerging/chw/index.html>

1. Roles, Advocacy and Outreach: two credits
2. Organization and Resources: one credit
3. Teaching and Capacity Building: two credits
4. Legal and Ethical Responsibilities: one credit
5. Coordination and Documentation: one credit
6. Communication and Cultural Competency: two credits
7. Health Promotion Competencies: three credits (not-core competency)
8. Practice Competencies - Internship: two credits (not-core competency)

Legislation and Rules

Similar to most states, Minnesota has not enacted occupational regulation of CHWs and does not define the CHW scope of practice in statute or rule. According to [Minnesota Statute 256B.0625, Subdivision 49](#), the state's Medical Assistance (MA) program covers care coordination and patient education services provided by a CHW if the CHW has received a certificate from the Minnesota State Colleges and Universities System approved community health worker curriculum.

Minnesota Statute 256B.0624 Subdivision 49 describes CHW covered services link:

<https://www.revisor.mn.gov/statutes/?id=256B.0625>

Medicaid/State Plan Amendment

Minnesota's Medicaid program, known as Minnesota Health Care Programs (including Medical Assistant and Minnesota Care), has covered CHW services since 2009. At this time, covered services are defined as "diagnosis-related health education" as specified by the CHW's authorized ordering provider. Many provider types may supervise CHWs, including physicians, dentists, public health nurses, and mental health professionals, among others.

The MN DHS CHW home page has a link to the [Minnesota Department of Human Services Provider Manual](#), which includes the most up-to-date information on enrollment and reimbursement for CHWs.

Only certain Medicaid recipients are eligible to receive educational services provided by a CHW, and the covered services are limited. These are described on the CHW homepage:

http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs16_140357

Examples of CHWs working in Minnesota:

The following are examples of CHW job descriptions that reflect the variety in duties depending on worksite:

- From [Community Health Worker, Sr. Job Description \(PDF\)](http://mnchwalliance.org/wp-content/uploads/2013/08/HennepinCountyHealth-CareHome.pdf), Hennepin County Medical Center Health Care Home, Minneapolis <http://mnchwalliance.org/wp-content/uploads/2013/08/HennepinCountyHealth-CareHome.pdf>
- From [Community Health Worker Job Description \(PDF\)](http://mnchwalliance.org/wp-content/uploads/2013/08/HennepinCountyHealth-CareHome.pdf), from the Intercultural Mutual Assistance Association, Rochester <http://mnchwalliance.org/wp-content/uploads/2013/08/HennepinCountyHealth-CareHome.pdf>

Minnesota CHW programs spotlights and resources:

- [Hennepin County Medical Center: Patients in Transition \(PITS\)](http://www.hcmc.org/clinics/Pediatrics/PatientsinTransition/HCMC_D_045855) http://www.hcmc.org/clinics/Pediatrics/PatientsinTransition/HCMC_D_045855
- [Community Dental Care](http://mnchwalliance.org/)
- [Minnesota CHW Alliance](http://mnchwalliance.org/) <http://mnchwalliance.org/>
- [MVNA: The Vital Role of the Community Health Worker](http://www.mvna.org/about/knowledge-center/community-health-workers/) <http://www.mvna.org/about/knowledge-center/community-health-workers/>

Appendix H: Profile of New Mexico's CHW Program

Background

New Mexico's community health workers (CHWs) are known as:

- Community Health Workers (CHWs)
- Promotores(as) de Salud
- Tribal Community Health Representatives (CHRs)

Overall program webpage: <https://nmhealth.org/about/phd/hsb/ochw/>

Established in 2008, the New Mexico Department of Health, Office of Community Health Workers' (OCHW) primary responsibility is to develop a standardized, statewide training program and a certification process for community health workers (CHWs). In 2014, CHWs were formally recognized by the state legislature. **Certification is voluntary and only for those who meet core competencies.**

Licensure is not offered or required.

- A FAQs document is located here: <https://nmhealth.org/publication/view/help/1764/>
- A list of OCHW Partners is located here: <https://nmhealth.org/publication/view/general/547/>

CHW's Standards/Training/Curriculum

The New Mexico Department of Health offers voluntary certification for CHWs and certification through grandfathering for CHWs who were practicing in the state before the passage of the Community Health Workers Act, on May 21, 2014. (See link to Act in "Legislation and Rules" section below.)

- The NM CHW Certification Board, established in 2015, acts as an advisory body to the secretary of health, making recommendations on core competencies and requirements and qualifications.
- The NM CHW Advisory Council (NMCHWAC) serves as an advisory group to the New Mexico Department of Health and as a critical partner working with the Office of Community Health Workers to develop a statewide training and certification process for CHWs. The NMCHWAC includes CHWs and meets monthly.

As there are two separate types of voluntary certification of CHWs, one for new CHWs and one for CHWs who had practiced in the state before the legislative action, the OCHW developed two separate applications for certification.

- New CHW application: <https://nmhealth.org/publication/view/form/2950/>
- "Grandfathering" application in English: <https://nmhealth.org/publication/view/form/1797/>
- Standardization of training is currently in development and should include a curriculum based on a defined set of core competencies. **Core competencies** are listed in the FAQs: <https://nmhealth.org/publication/view/help/1764/>

There are two levels of certification: Generalist and Specialist. Specialist certification can include specialties in one or more of the following areas: clinical support skills, heart health, behavioral health, chronic disease, maternal and child health, or asthma.

Legislation and Rules

The formal recognition and utilization of CHWs as an essential part of a cost-effective health care system received legislative support with the passage of the [Community Health Workers Act](#) during the 2014 legislative session.

- Act: <https://www.nmlegis.gov/Sessions/14%20Regular/final/SB0058.pdf> .
- Additional legislation: <http://164.64.110.239/nmac/parts/title07/07.029.0005.htm>

Appendix I: Profile of Oregon’s CHW Program

Oregon uses the term “**Traditional Health Worker**” (THW) and it includes five types:

- CHWs
- Peer Support specialists
- Peer Wellness Specialists
- Personal health navigators
- Birth doulas

Overall program webpage: <https://www.oregon.gov/oha/oei/Pages/Traditional-Health-Worker-Program.aspx>

Currently undergoing updating, but **there is a registry of the THW and a registry/listing of approved programs**; they also have a list of organizations that employ THWs which is helpful to both those looking for work and for other organizations to talk with to understand the roles the THWs play.

Also, there is a document with tips for contracting with organizations to aid the THWs and help the organizations integrate the THWs into their organizations’ work. It also outlines the benefits of having THWs, and a table that discusses the type of THW and the populations served.

<https://www.oregon.gov/oha/OEI/Documents/Traditional-Health-Worker-Tip-Sheet-9-2016.pdf>

THW’s Standards/Curriculum- Key document

This is the founding first work done to start Oregon’s program and outlines the core competencies, education, and training requirements:

<https://www.oregon.gov/oha/oei/reports/The%20Role%20of%20Non-Traditional%20Health%20Workers%20in%20Oregon's%20Health%20Care%20System.pdf>

The standards for the overall THW curriculum are outlined in the administrative rules (see below) and this first report. The term “non-traditional” health workers was first used to distinguish from mainstream providers (doctors, nurses, etc.) and then the advisory group and others felt “traditional” was the better term. It still holds an original “draft” watermark after all the years, but has not been updated or revised since first completed in 2012.

Legislation and Rules:

- Overall webpage: <https://www.oregon.gov/oha/oei/Pages/THW-RAC.aspx>
- Original legislation is HB 2024 available at: <https://www.oregon.gov/oha/OEI/Documents/HB-2024.pdf>
- Oregon statutes: <https://www.oregonlaws.org/ors/413.600>
- Admin rules (see section 410-180-0370 that outlines the curriculum standards) <https://www.oregon.gov/oha/OEI/Documents/THW-OAR-410-Rule.pdf>

Medicaid/State Plan Amendment

As part of the original 1115 waiver for the CCOs, Oregon agreed to commit to train 300 new CHWs by 2015, and CMS required the Oregon Health Authority to create standards for the training to allow billing for services under Medicaid. The amendment is faded but it describes required “supervision” by each of the types of THWs.

State Plan Amendment document: <https://www.medicaid.gov/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/OR/OR-12-007.pdf>

The renewal of the waiver was just approved in January 2017 for another five years. The terms and conditions document notes THWs, and Oregon also describes THWs in detail in the application materials submitted. There is no funding attached for ongoing support to the THW program which Oregon applied some SIM dollars to support and that grant is due to end spring 2017. The agency thinks the staff oversight position and registries should be maintained, but no funds to help offset the cost of training programs for new THWs should be available unless they find foundational support.

Oregon’s waiver renewal document- <http://www.oregon.gov/oha/HPA/HP-Medicaid-1115-Waiver/Documents/Waiver-Renewal-Submission.pdf>

From the waiver renewal application: From page 9 (of 92) in application appendix:
<http://www.oregon.gov/oha/HPA/HP-Medicaid-1115-Waiver/Documents/Waiver-Renewal-Appendices.pdf>

Traditional Health Workers

Traditional Health Workers (THW) include community health workers, peer wellness specialists, patient navigators, and doula and are an integral part of effectively implementing the coordinated care model and reducing health disparities across all delivery systems, including reaching fee-for-service members. THWs take health care beyond the four walls of clinics and hospitals, out into homes and the community, supporting healthcare transformation in a variety of ways.

By focusing on culturally sensitive and linguistically appropriate approaches, THWs support adherence to treatment and care plans, coordinate care and support system navigation and transitions, promote chronic disease self-management, and foster community-based prevention.

Examples of THWs working in Oregon:

The legislature gave money to Oregon’s new Community Care Organizations (CCO) in the first years of the waiver with some of them investing in CHWs: lists of those and some other projects funded by the CCOs are available at: <http://www.oregon.gov/OHA/HPA/CSI-TC/Pages/Transformation-Funds.aspx>

Appendix J: DRAFT CHW Core Curriculum Competencies and Curricular Considerations

Effective Communication and Documentation Skills, including Computer Literacy

Effective and purposeful communication is listening carefully and communicating respectfully in ways that help build trust and rapport with clients, community members, colleagues, and other professionals. Effective communication includes a mix of listening, speaking, gathering and sharing information, and resolving conflict. CHWs are open about their roles, responsibilities, and limits. CHWs protect client privacy and confidentiality. They convey knowledge accurately, clearly, and in culturally aware and responsive ways. They are able to use language and behavior that is responsive to the diversity of cultures they encounter in their work, including with clients, community members, and other professionals. CHWs help promote coordinated and effective services by documenting their work activities, including writing summaries of client and community assessments. They often present information to agency colleagues or community partners about their clients and the issues they face. CHWs use computer technology and communicate when possible in the primary language of the client and/or make alternative arrangements to utilize appropriate linguistic capacities. They respect cultural experience and preferences and use community relationships that they may bring to their work.

In developing the draft CHW Core Curriculum Competencies and Curricular Considerations, the CHW Subcommittee asked representatives of Delaware accountable care organizations, community health centers, educational institutions and other community partners for their review and feedback.

The CHW Subcommittee’s preliminary work includes both the competencies and competency levels for curricula considerations:

Level 1: Core competency, which all CHWs would need to have

Level 2: Intermediate

Level 3: Advanced

The proposed “level” is indicated next to each competency.

Competency includes the ability to:

- Practice careful listening, repeating back important information as necessary to confirm mutual understanding, continually working to improve communication, and revisit past topics as trust develops with client. (1)
- Pay attention to expressive (non-verbal) behavior. (1)
- Ask neutral, open-ended questions to request relevant information. (1)
- Speak clearly and honestly. (1)
- Use language that conveys caring and is non-judgmental. (1)

- Use appropriate terms and explain terms or concepts whose meanings may not be obvious to clients, community members, or professional colleagues. (1)
- Clarify mutual rights and obligations, as necessary, such as client confidentiality or CHW reporting responsibilities. (1)
- Use written and visual materials to convey information clearly and accurately. (1)
- Take care to prevent situations involving conflict. Address conflicts that may arise in a professional and safe manner. (1)
- Recognize the importance of documentation to program evaluation and sustainability and to helping clients achieve their goals. (1)
- Organize one's thoughts and write at the level necessary for communicating effectively with clients, other community members, supervisors, and other professional colleagues. (1)
- Comply with reporting, record keeping, and documentation requirements in one's work. (1)
- Use appropriate technology, such as computers, for work-based communication, according to employer requirements. (1)

Cultural Competency

Culture is defined here as beliefs, values, customs, and social behavior shared by a group of people with common identity. Identity may be based on race, ethnicity, language, religion, sex, gender identity, sexual orientation, disability, health condition, education, income, place, profession, history, or other factors. Culture also includes organizational cultures, which are reflected in how organizations deliver services. CHWs act as cultural mediators. CHWs educate and support providers in working with clients from diverse cultures, and help clients and community members interact effectively with professionals working in different organizations to promote health, improve services, and reduce disparities. CHWs encourage and enable clients to participate in decisions that affect their lives, families, and communities.

Competency includes the ability to:

- Describe different aspects of community and culture and how these can influence peoples' health beliefs and behavior. (1)
- Describe ways the organizational culture within provider agencies and institutions can affect access, quality, and client experience with services. (1)
- Explain how one's own culture and life experience influence one's work with clients, community members, and professional colleagues from diverse backgrounds. (1)
- Be respectful and culturally aware during interactions with clients. (1)
- Employ techniques for interacting sensitively and effectively with people from cultures or communities that differ from one's own. (1)
- Support the development of authentic, effective partnerships between clients and providers by helping each to better understand the other's perspectives. (1)

- Make accommodations to address communication needs accurately and sensitively with people whose language(s) one cannot understand. (1)
- Advocate for and promote the use of culturally and linguistically appropriate services and resources within organizations and with diverse colleagues and community partners. (1)
- Advocate for client self-determination and dignity. (3)

Professional Skills and Conduct, including Interpersonal Skills, Time, and Stress Management

Professional skills for CHWs include how to handle ethical challenges as they address legal and social challenges facing the clients and communities they serve. Client confidentiality and privacy rights must be protected in the context of employer and legal reporting requirements. Care for clients must be balanced with care for self. CHWs understand that it is necessary to be aware of one's own emotional and behavioral responses to clients and community members and to manage personal feelings productively to maintain effectiveness. CHWs must be able to act decisively in complex circumstances but also to utilize supervision and professional collaboration. They must observe agency rules and the regulations governing public and private resources while exercising creativity to help community members meet their individual and family needs.

Competency includes the ability to:

- Practice in compliance with the Delaware Code of Ethics for Community Health Workers. (1)
- Observe the scope and boundaries of the CHW role in the context of the agency team and agency policy. (1)
- Respect client rights under the Health Insurance Portability and Accountability Act (HIPAA) and applicable agency rules. (1)
- Understand issues related to abuse, neglect, and criminal activity that may be reportable under law and regulation according to agency policy. (1)
- Maintain appropriate boundaries that balance professional and personal relationships, recognizing dual roles as both CHW and community member. (1)
- Seek assistance from supervisors as necessary to address challenges related to work responsibilities. (1)
- Establish priorities and organize one's time, resources, and activities to achieve them. (1)
- Utilize and advocate as necessary for supervision, training, continuing education, networking, and other resources for professional development and lifelong learning for self and colleagues. (1)

Advocacy and Community Capacity Building, and Outreach (Community Health Outreach and Advocacy)

Advocacy is working with or on behalf of people to exercise their rights and gain access to resources. Capacity is helping people develop the confidence and ability to assume increasing control over decisions and resources that affect their health and well-being. Community capacity building involves

promoting individual and collective empowerment through education, skill development, networking, organizing, and strategic partnerships. Capacity building requires planning, cooperation, and commitment, and it may involve working to change public awareness, organizational rules, institutional practices, or public policy.

Advocacy and capacity building go hand-in-hand and can help create conditions and build relationships that lead to better health. Outreach is the process of contacting, engaging with, and helping people to learn about and use resources to improve their health and well-being. Outreach may be conducted with individuals, groups, organizations, and at the community level. In outreach, CHWs “meet people where they are,” building relationships based on listening, trust, and respect. This can take place in diverse settings, including where people live, work, learn, worship, socialize, play, exercise, and conduct business. There are a variety of outreach methods, such as phone calls, in-person conversations, group presentations, distribution of print and electronic information, and social media. Effective outreach is based on learning about community needs and strengths, knowledge about available resources, and sensitivity to personal and cultural dynamics that affect behavior and relationships.

Competency includes the ability to:

- Conduct outreach with attention to possible safety risks for self, clients, and colleagues. (1)
- Initiate and sustain trusting relationships with individuals, families, and social networks. (1)
- Advocate on behalf of clients and communities, as appropriate, to assist people to attain needed care or resources in a reasonable and timely fashion. (2)
- Apply principles and skills needed for identifying and developing community leadership. (2)
- Facilitate constructive discussion in informal and group settings with clients and their families. (2)
- Establish and maintain cooperative relationships with community-based organizations and other resources to promote client services, care, education, and advocacy. (2)
- Use a range of outreach methods to engage individuals and groups in diverse settings. (2)
- Build and maintain networks, and collaborate with appropriate community partners in capacity building activities. (3)
- Develop and implement outreach plans in collaboration with colleagues, based on individual, family, and community needs, strengths, and resources. (3)
- Communicate with providers and service organizations to help them understand community and individual conditions, culture, and behavior to improve the effectiveness of services they provide. (3)

Health Coaching; Education to Promote Healthy Behavior Change

Education for healthy behavior change means providing people with information, tools, and encouragement to help them improve their health and stay healthy over time. CHWs respect people’s experience and their abilities to learn, take advantage of resources, and set priorities for changing their own behavior. CHWs work with clients, family and community members, and providers to address issues

that may limit opportunities for healthy behavior. The CHW acts as educator and coach, using a variety of techniques to motivate and support behavior change to improve health.

Competency includes the ability to:

- Encourage clients to identify and prioritize their personal, family, and community needs. (1)
- Encourage clients to identify and use available resources to meet their needs and goals. (1)
- Provide information and support for people to advocate for themselves over time and to participate in the provision of improved services. (1)
- Provide on-going support and follow-up as necessary to support healthy behavior change. (1)
- Identify and share appropriate information, referrals, and other resources to help individuals, families, groups, and organizations meet their needs. (1)
- Realize the widespread impact of trauma and understand potential paths for recovery.*
- Recognizes signs and symptoms of trauma in clients, families, staff, and others in the community.*
- Integrate knowledge about trauma into policies, procedures, and practice.*
- Resist re-traumatization.*
- Use a variety of strategies, such as role modeling, to support clients in meeting objectives, depending on challenges and changing conditions. (2)
- Apply information from client and community assessments to health education strategies. (2)
- Apply multiple techniques for helping people understand and feel empowered to address health risks for themselves, their family members, or their communities. (Examples may include informal counseling, motivational interviewing, active listening, harm reduction, community-based participatory research, group work, policy change, and other strategies.) (2)
- Coordinate education and behavior change activities with the care that is provided by professional colleagues and team members. (2)
- Develop health improvement plans in cooperation with clients and professional colleagues that recognize and build upon client goals, strengths, and current abilities to work on achieving their goals. (3)

Service Coordination, System Navigation, Triage, and Safety

Coordination of care and system navigation for individuals and families means that CHWs help people understand and use the services of health providers and other service organizations. They also help address practical problems that may interfere with people's abilities to follow provider instructions and advice. CHWs help bridge cultural, linguistic, knowledge, and literacy differences among individuals, families, communities, and providers. They help improve communications involving community members and agency or institutional professionals. CHWs understand and share information about available resources, and support planning and evaluation to improve health services.

Competency includes the ability to:

- Work collaboratively as part of a care team. (1)

- Obtain and share up-to-date eligibility requirements and other information about health insurance, public health programs, social services, and additional resources to protect and promote health. (1)
- Provide support for people to understand and use agency and institutional services. (1)
- Make referrals and connections to community resources to help individuals and families meet basic social needs. (1)
- Provide support for clients to use provider instructions or advice, and convey client challenges to providers. (2)
- Build clients' abilities to participate in making decisions about their care. (2)
- Inform care providers, to the extent authorized, about challenges that limit the ability of clients to follow care plans and navigate the health care system, including barriers outlined in the Americans with Disabilities Act. (2)
- Provide care coordination, which may include but not be limited to facilitating care transitions, supporting the completion of referrals, and providing or confirming appropriate follow-up. (2)
- Assist in developing and implementing care plans in cooperation with clients and professional colleagues. (Care plans should be based on needs and resource assessments. Plans should describe how each party will help meet the goals and priorities defined in collaboration with clients.) (3)

Public Health, Community Knowledge and Needs Assessment

The knowledge base for CHW practice is strongly influenced by the field of public health. Public health is a science-based discipline that focuses on protecting and promoting population health, preventing illness and injury, eliminating health inequities, and working to improve the health of vulnerable communities and populations. CHWs, like other public health practitioners, understand that individual health is shaped by family, community, and wider “social determinants of health.” CHWs often use their knowledge of the larger contexts of clients’ lives to provide support for them to overcome barriers or improve conditions that affect their health.

Assessment is the collection, synthesis, and use of information to help understand the needs, strengths, and resources of the individuals and communities CHWs serve. CHWs share this information with clients, professional colleagues, and community partners to help plan and carry out effective programs, services, and advocacy based on shared priorities. They engage people in honest and often difficult discussions about health status and behavior. They also gain insights about needed resources and changes and share their understanding with appropriate parties to help achieve desired outcomes. Assessment is an ongoing process that, when combined with regular evaluation of progress, helps assure effective client and community-centered care.

Competency includes the ability to:

- Explain how plans for supporting individuals and families relate to wider social factors that influence health. (1)
- Explain the relationship between health and social justice. (1)

- Use data and evidence-based practices in efforts to support clients in reaching their goals. (3)
- Gain and share information about specific health topics most relevant to the populations and communities being served. (3)
- Promote efforts to prevent injury and disease, including those that require policy changes, and support effective use of the health care system. (3)
- Promote health equity and efforts to reduce health disparities through engagement with clients, professional colleagues, and community partners. (3)
- Engage in systematic problem solving — including assessment, information gathering, goal setting, planning, implementation, evaluation, and revision of plans and methods, as necessary — to achieve shared objectives. (3)
- Gather and combine information from different sources to better understand clients, their families and their communities. (3)
- Assess barriers to accessing health care and other services. (3)
- Help people to identify their goals, barriers to change, and supports for change, including personal strengths and problem-solving abilities. (3)
- Share community assessment results with colleagues and community partners to inform planning and health improvement efforts. (3)
- Continue assessment as an on-going process, taking into account changes in client circumstances and the CHW-client relationship. (3)

Curricular Considerations

Case Management	Interpersonal Skills
Community Health Education	Legal Aspects - HIPAA
Community Health Planning	Legal Aspects - Public Policy
Community Needs Assessment	Legal Aspects - ADA
Critical Thinking	Literature Review
Cultural Diversity	Medical Terminology
Data Analysis	Oral and Written Communication
Documentation Requirements	Organizational Skills
Email	Problem Solving
Environmental Health	Professional Behavior
Ethics in Healthcare	Public Safety
General Office Software (Documents)	Reading Comprehension
Group Dynamics	Scope of Practice
Health Promotion	Social Determinants of Health
HIPAA	Statistical Applications
Individual Needs Assessment	The Healthcare System
Internet Search	Time Management
Interpersonal Relations	Trauma Informed Care



2017 Cancer Symposium

John H. Ammon
Medical Education Center
Christiana Hospital campus

Save the Date

Thursday, October 26, 2017
6 – 8:30 p.m.

Save the Date: Thursday, October 26, 2017 | 6 – 8:30 p.m.

Embracing Palliative Care: A Physician's Role

The Helen F. Graham Cancer Center & Research Institute presents the 2017 Cancer Symposium on Thursday, October 26. This year's symposium and dinner program Embracing Palliative Care: A Physician's Role will help to advance the knowledge and practice of healthcare professionals who impact the quality of life for their patients and families who are experiencing life threatening illnesses. A panel discussion local experts will follow.

You will receive an invitation via e-mail in the near future. In the meantime, please mark your calendar for October 26.

We look forward to seeing you at this year's Cancer Symposium.



CHRISTIANA CARE
HEALTH SYSTEM

Helen F. Graham Cancer Center
& Research Institute

An Interview with Vicky Cooke

The Former Executive Director of the Delaware Breast Cancer Coalition



Tim Gibbs: What got you into this work?

Vicky Cooke: My career started in non-profits, with Girls Incorporated, and I was very much an advocate for issues for young girls and young women. When I was diagnosed with breast cancer, and I was working at Girls Inc., I had an opportunity come along at the Delaware Breast Cancer Coalition, when it was just a grassroots organization. Being a survivor, you have a great sense of wanting to give back to the community and to share your experience. It becomes a sisterhood with other survivors where you don't want other survivors to experience what you've experienced. So I got involved with DCBB as a volunteer; I did a lot of the fundraising and helped them get things off the ground. It grew and got to the point where they needed an Executive Director. Based on my non-profit experience, I was asked to be the Director, and I had already worked with them for 5 years as a volunteer. I was coming on to

work as a new Director for an organization that had only done some fundraising, so when I started we immediately identified what some of the needs were in Delaware.

I was diagnosed [with breast cancer] when I was 44 and that was considered to be a young woman. So we started a program that was called the Young Survivors in Action because there were an alarming number of younger women being diagnosed. Breast cancer wasn't just a disease affecting your mother and grandmother; it was affecting younger women as well. That was one of the first programs we developed and submitted a grant proposal for, which got funded, and we then started to partner with the State of Delaware. They were looking for outreach people who would go out and identify women that needed mammograms. Little by little, we were able to get some contracts, while also performing a service, and creating some program delivery. From there, we grew the agency to be Delaware's most trusted resource for breast cancer.



Tim Gibbs, Vicky Cooke, and new Delaware Breast Cancer Coalition Executive Director, Eileen Filliben Edmunds

I like to say our programs now form a circle. We go out and we try to identify women who need to be screened, and we educate them about risk. There is no prevention for breast cancer, but you can reduce your risk through things like maintaining a healthy lifestyle. We have a strong outreach program, if someone needs to be screened, we can screen them in our mammography van. If someone gets diagnosed on the van, or elsewhere, then we have program that helps them through their breast cancer journey, and that is our peer mentoring program. This program connects women with similar circumstances and needs, and their mentor can help them through their journey. Some people may have more than one mentor depending on their treatment and other factors.

We also educate the public about the newest advancements in breast cancer through our breast cancer update, which will happen in April. It's free for the public and every year about 300 to 400 people attend. We have medical professionals and researchers presenting during this one-day symposium. We also encourage advocacy. If you've been diagnosed or breast cancer is something that you feel strongly about then we have advocacy efforts as well...it's a full circle of service and delivery to the community.

TG:*What educational background did you have?*

VC: I have no medical background at all...I went to the University of Delaware and Villanova...I think what positioned me for this job was my work in the non-profit community. If someone were to come into this new director role in this organization with a medical background, it would've looked completely different than it looks today. It's that non-profit experience, it is understanding advocacy and working on a cause that has been helpful.

TG:*What changes have you seen, whether these are changes in technology or changes in crowd attitudes, with self-exams, and getting mammographies over the past 25 years?*

VC: I would say over the last 24 years since I've been diagnosed, not enough change has been made. We have better treatment and better screening, but we still have the ability to end this disease. Maybe there is a specific prevention, or there is there a vaccine, like the vaccine for cervical cancer, that could end one of these types of breast cancer. People don't die of a breast cancer tumor, people die of metastasis. How do find out how to control metastasis, and how do we end the cancer metastasizing? All of this is political. It's system changes that need to be made in the research community. Even research that fails is as important as research that succeeds...but there are politics in research that keep things from moving along. You may have a young researcher with a really good idea, but the politics of research might prevent this young researcher from having an avenue to put this idea out there...as people in the community and those affected by the disease, we need to think about where are these dollars going, where is this peer review, where is the reporting, where is the reporting done, where are the consumers on the IRBs, and what is the representation of survivors in the research community.

Is the mortality rate lower? Absolutely, I have been diagnosed twice, and I sit here like I have never had the disease at all. Even people who have been diagnosed at later stages and live with metastasis, for some it has just become living with a chronic disease. My husband had diabetes, and to me the diabetes was scarier than the breast cancer because you couldn't control it. We have made progress to a certain extent, but when you look at the millions, probably billions of dollars that have been spent on this disease, and to only be where we are 24 years later, it's discouraging. And, if I had to sit here 20 years later having this same conversation, how sad would that be? With all of our progress and technology...what's behind this that we don't have figured out?

...there are still way too many people being diagnosed. In some cases this could be because there is better protection and ways of finding breast cancer earlier. Reducing health risks certainly gives you a better chance of going through treatment and living a full, regular life after breast cancer. Again, when I was diagnosed, it was still considered sort of a death sentence. I remember coming into work and having to show them I was ok. The other progress that was made was with having a lumpectomy. I had a lumpectomy; I didn't have to have a mastectomy. But before that, everyone had a mastectomy, and in some cases terrible, radical mastectomies, probably for people who had estrogen positive breast cancer, that was a lump that could've been removed. So in that sense, we have made progress, but is that the only kind of progress we want to make? I think women, family, and loved ones all deserve more.

TG:*Over the last 20 to 30 years, longevity has increased dramatically. Is there an age point at which the intervention and treatment are worse than just living out your days? For example, would a woman in her 90's go through with treatment?*

VC: Probably, she wouldn't go through with this treatment because they would determine the aggressiveness of the tumor, and in somebody 90 years old, it might not be that aggressive. So with someone y older, they would look at the diagnosis and say this is a slow-growing, non-aggressive tumor and then they may possibly do some radiation. However, if they were 90 and they did have somewhat of an aggressive tumor, it would depend on their health and if they could even withstand a breast cancer treatment...you

have to look at the quality of life. If you're 90, 80, or even 70, it depends on the aggressiveness of the cancer, and on quality of life. Some of that would be a very personal decision, and some of that would be a recommendation based on age and health, and I think that goes for any cancer, not just breast cancer.

TG: *In other types of cancer, for example, prostate cancer in men, there have been some considerable changes in terms of the guidelines for screening. Have there been similar changes with breast cancer?*

VC: There have, and we follow the [Delaware] cancer consortium's recommendations. We still say that women over 40 should get an annual mammogram. If you need a mammogram earlier than that based on your family history, then that is something to talk to your doctor about. I was diagnosed at 44 and I have 3 daughters. Their doctors all recommended they get a baseline mammogram at the age of 34. Often they suggest screening ten years before [your relative's] diagnosis when the relationship is that close. We've made such great progress with mammography, and colorectal cancer screening as well. Even history of breast cancer in a man's family should be revealed to his physician as well.

TG: *What about breast cancer in men?*

VC: Well it's only 1%, and usually there is a family history of some sort. The doctors can speak to that better than I can, but it doesn't affect men randomly the way it does women... usually breast cancer in men has a genetic link. To clarify, when I refer to breast cancer in women, I am including the knowledge that it does affect men, although it's such a small number. And I should note, our programs certainly would cater to men as well should they be interested. For a while, we had an alarming number of men involved for the size of our state. We had about 10 or 11 men involved with us and that just seemed like a high number in Delaware. That was just who we knew, I'm sure there were others we didn't know as well.

TG: *Can you tell me about some of the disparities- whether they are racial, socioeconomic, gender based- is Delaware in a good position in terms of screening everyone that needs to be screened, or are there subset populations that need more attention and outreach?*

VC: Well, I would say organizations like ours have really focused on screening the underserved. We want to be culturally competent and we want to serve everyone who needs to be served, and we pride ourselves in that respect. Our staff represents people in the community. When we go out and do outreach, we really have had success getting into different communities. I will say, at this point we have broken down many barriers. It's not just the Delaware Breast Cancer Coalition, it's the partners, and it is understanding the culture of a community. We have seen that African American women are better at getting screenings than white women. Many white women will put off their screenings, while African American women have heard the message, so we've made great progress with that community. We've made great progress with the Hispanic community, we have Spanish speaking staff who will do everything from calling, to making



appointments, following up, greeting women, and getting them on the van [for screening]. Our retention of women and the showing up rate is strong because we have Spanish-speaking staff who can interpret for them, so we've done a good job, along with other people, of meeting the needs of the community of those populations. We're also in the process of hopefully hiring a woman who will do outreach for us in Sussex county with the Haitian population, which is growing in Sussex county and Dover. Haitians are moving into this state in high numbers from other states... so we are going to take a leadership role in breaking through the Haitian community. This is something we have done anyway with different populations. We're a little different than we were 17 years ago when I first started in that we aren't just about getting women screened, or just about providing some services to women who've been diagnosed, we look at women who are diagnosed and understand they have all this stuff going on in their life, good or bad, and now you just put breast cancer on top of it.

So now you've just complicated everything in their lives, but there are still many other things going on underneath the breast cancer, and it's important to remember those are still there.

I think because of my non-profit background I've developed the understanding about why it's important to partner with, and be involved in, the non-profit community and with other social services. We often need to refer people out for the other issues they have, whether it is a single mom, or somebody who needs financial assistance. Right now we're helping a woman who is homeless. She's able to live with her daughter, but she has some belongings and she needs somebody to help her pay for a storage unit. If not, she has no place to put these belongings and would lose everything in addition to going through a breast cancer journey...I could tell you stories that would just break your heart about people who need things. So when you ask about working with different communities, we work with the uninsured, underserved, all the people who would need services like ours, but we also refer them out when necessary.

TG: Two other communities I wanted to ask about include the Asian community, in particular in Hockessin, and then the lesbian community. We frequently hear about health challenges and disparities in the gay and lesbian communities being disproportionate. What the position on that?

VC: We have a great relationship with Camp Rehoboth and the different organizations in the Rehoboth area. They've embraced us and they've even raised funds for us. We've got a good relationship, but it is hard to break into the community...I think it's better than it used to be before. I think people didn't want to come out and tell you, and there was stigma, a lot of that has diminished. I think people are so much more accepting now. Our organization is very accepting and always has been. Breast cancer doesn't discriminate, and everyone who needs help deserves to have that help. We have really reached out to make sure the lesbian community to make sure they know about getting screened. We used to do the "removing the barriers" program, and do workshops...we have members of our staff that are lesbian, and again it's because we want to project the image that we are inclusive. We want our faces to be the faces of the community.

TG: You mentioned 'image' which is a perfect transition to another question I have. Through the television, the hallmark movies, there are enough stories out there that tell us having a mastectomy is a life changing challenge in terms of self-image. From your perspective as an individual, what is the reality behind that? How many women really struggle post double radical mastectomy with their image, or with how their partner sees them? How much of that is the real stuff versus what we've been?

VC: It's more than just the fact that you've had your breasts removed, it's also the fact you've been diagnosed with a disease that could be life threatening, all of that will affect someone. The image part, people will address, and certainly struggle. However, there is also phenomenal plastic surgery out there right now and reconstruction efforts, there is something that pretty much fits everyone's needs...although not everybody needs that.

I've been diagnosed twice. I had a lumpectomy the first time. It wasn't too terribly disfiguring, and I lived with it, and my husband didn't care...I by rights, and by law, am entitled some sort of reconstruction if I choose to have it. So when I was diagnosed two years ago- this is sort of a new development- they are finding women who were diagnosed with estrogen positive breast cancer years ago are sometimes re-diagnosed. It's a brand new diagnosis, and it's not the result of having breast cancer before...so I have now had it twice...I prepared myself and asked my staff what do I need to know. I had already determined what surgery I was going to have and I walked into my doctor's office and asked about reconstruction, and she looked at me and said, why would you do that? I said because I've been diagnosed for the second time, and this is what I need to do. She said back I just needed a lumpectomy.

But, there will be people who will think more is better. They may go into the doctor's office and say I want a double mastectomy, I don't even want to deal with this again, but that's no guarantee. Your breast tissue goes from your shoulder to your waist. You can cut off the fatty parts of your body, but that doesn't necessarily mean that you're cured and that's the end. So I think a person being open to what they need really is important. So if your doctor says I think you need a lumpectomy, then consider it. It's personal choice, but consider it. If you want you could have a prophylactic mastectomy like Angelina Jolie, and there is the BRCA

gene [to consider], there are other cancers...all I can say is it's important to sit down with the doctor and talk about your needs, and get second opinions.

TG: What can you tell me about Pinkwashing?

VC: So, that is one of our advocacy points. You have to look at what's really happening out there. [Pinkwashing] is when companies have capitalized on a disease, and I'll use the example of M&M's. M&M's came out with these pink and white candies for breast cancer awareness and they said they were going to donate a dollar to breast cancer for each bag sold. So did they really give a dollar? They really just raised the price of a normal bag of M&M's and then gave a dollar. Somebody who buys a pink mixer for example, because the manufacturer says they'll give \$25 to breast cancer if you buy the pink mixer, should just give \$25 directly to the cause instead having the money go to a company trying to make money. Companies have made so much money off of breast cancer. If you look around we're not a real "pink" organization... People have gotten so caught up with wearing pink but there's so much more to it.

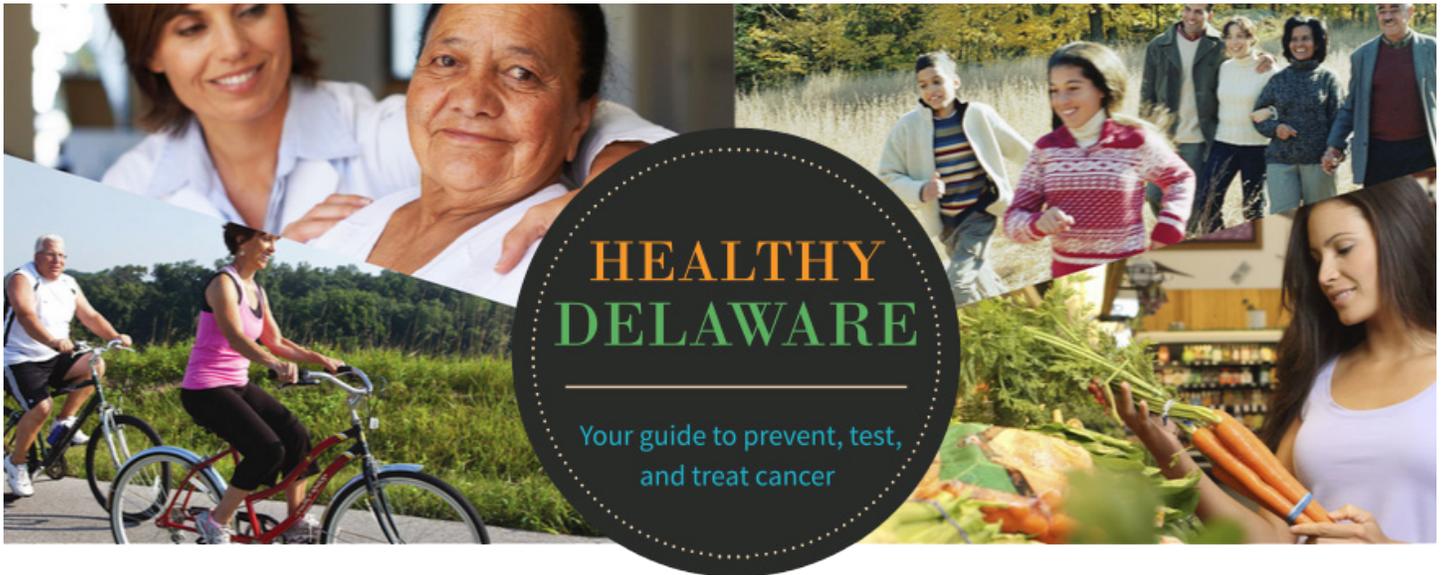
TG: What impact, if any, from a positive standpoint, did the Affordable Care Act have for the population that DBCC works with (screening, prevention, treatment, etc.)? And, if the new administration in Washington makes significant changes to the ACA, what fears do you have on how it will impact the clients?

Vicky Cooke is the former Executive Director of the Delaware Breast Cancer Coalition, Inc. (DBCC). She retired in January 2017 after a laudable career with over 45 years of non-profit management and program development experience. As a two-time breast cancer survivor, Vicky spent much of her career as an advocate on behalf of breast cancer issues in Delaware. She served as a volunteer board member of DBCC for five years, helping to raise funds and serving as a spokesperson for the organization's grassroots projects. In 2000, Vicky was hired as DBCC's first Executive Director and expanded the agency to a statewide organization developing programs and services that address the breast cancer needs of women and men in Delaware and the tri-state region. From breaking down barriers to mammography screening to helping to support a newly diagnosed patient, Vicky was and continues to be an engaged and highly dedicated community member.

She attended the University of Delaware and Villanova University. She is a former member of the National Breast Cancer Coalition's Board of Directors and a graduate of NBCC's Project LEAD and Clinical Trials LEAD. Vicky served and continues to serve on many community coalitions including the Delaware's Cancer Consortium, Highmark's BluePrints for the Community Advisory Council, and various local cancer agency boards. While she is now retired, she has agreed to chair the Delaware Breast Cancer Coalition's Sussex County Association. Vicky is the mother of three grown daughters, has nine grandchildren, and a dog named Maggie. In June 2017, Vicky was awarded the inaugural Victoria Cooke Leadership Award for her vision and direction at the Coalition. She has offered incredible support and leadership to so many survivors, members of the medical community, business leaders, and friends with distinguished grace and humility. Subsequent award recipients will be recognized for their years of service, support of breast cancer survivorship, leadership in healthcare delivery and research, generous philanthropy, and cultivation of businesses in the fight against breast cancer.

VC: I'm not sure about the ACA and the impact it had on the people we serve, but first of all, in Delaware we have such great cancer support medically, through programs like the cancer treatment program. If someone is underserved or under-insured, they can go through the Screening for Life program, and they're guaranteed screening. Anybody in Delaware can be screened. The ACA hasn't had an impact on who can be screened.

I would say there is no excuse for someone not to be screened; the money is available one way or another. Getting a mammogram isn't an issue. If you were underserved and you were diagnosed with cancer and you're in the cancer treatment program, you're guaranteed treatment for 2 years. So Delaware has that covered...what we did see was people with insurance, and their deductible was so high, their co-pay was high, their premium was high, they had insurance but couldn't afford to be treated. And I can't tell you how many women came through this organization needing financial assistance because they couldn't afford to be treated while they had insurance. That isn't something that's being talked about...now I will also say that I don't know anyone in the state who was turned away for any reason. Whether that was with the help hospitals and the doctors being accommodating, or organizations like ours helping pick up some of the financial assistance...but [cost] is still a huge problem for those with insurance and that to me is a huge issue.



HEALTHY DELAWARE

Your guide to prevent, test,
and treat cancer



Protect your skin from the sun's harmful rays.

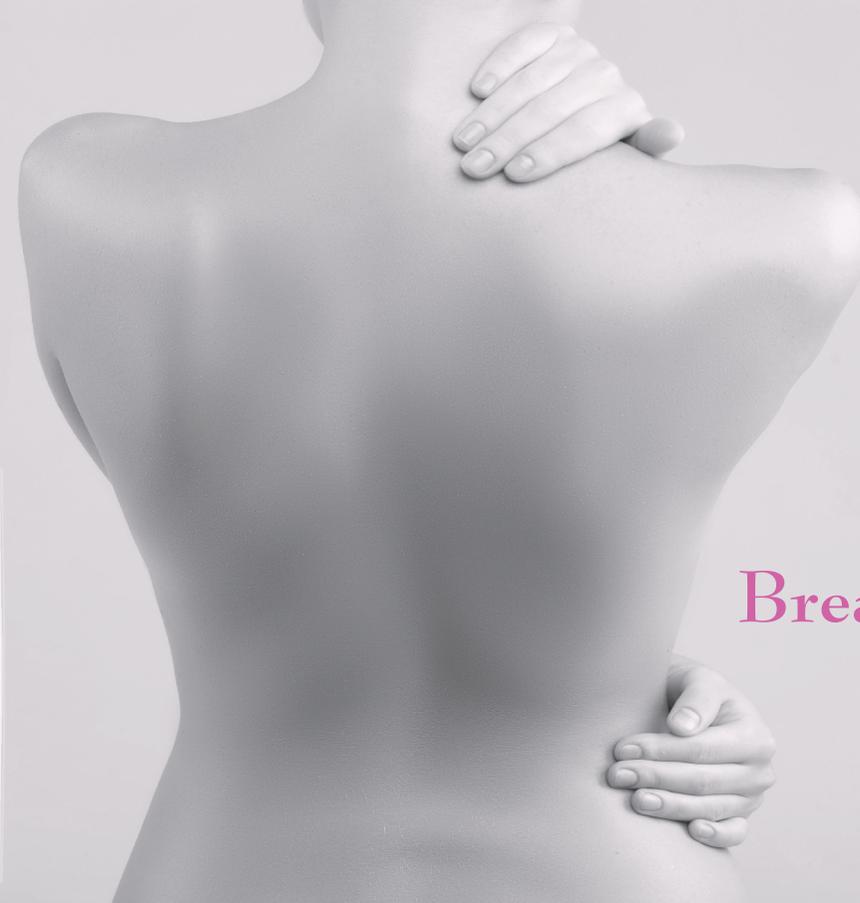
Delaware ranks third nationally for skin cancer diagnosis. With summer right around the corner, we encourage you to educate yourself on this highly preventable disease with ways to [stay sun safe all year long](#).

Everyone is at risk for skin cancer. Protection from damaging and dangerous ultraviolet (UVA and UVB) radiation is important year-round. Ultraviolet radiation from the sun and indoor tanning damages the epidermis, the skin's top layer. Long-term sun exposure, sunbathing, using indoor tanning, or having sunburns increases your chance of developing skin cancer, the most common form of cancer in the United States. Sun exposure also causes premature aging, wrinkles, age spots, and uneven skin tone. But protecting your skin is easy if you do these simple things:

1. **Apply sunscreen** to your entire body 30 minutes before going outside.
2. **Use a water-resistant sunscreen** with UVA and UVB protection and a broad-spectrum SPF 15+
3. **Reapply sunscreen** every two hours or immediately after swimming or excessive sweating.
4. **Seek shade**, especially between 10:00 a.m. and 4:00 p.m.
5. **Wear wide-brimmed hats** to cover your head, face, neck and ears.
6. **Protect your eyes** with sunglasses that block 99% or more of UV light.

Damaging rays can cause skin cancer and melanoma that can threaten your life. Make sure you'll be here to enjoy every summer to come by knowing the facts about what can put you at risk.

1. The sun's rays reach you on cloudy or hazy days and reflect off of water and sand.
2. People with light complexions are more likely to sunburn and should use a broad-spectrum SPF 15+.
3. If you have a family history of skin cancer, you're more likely to develop it, so be sure to get checked.
4. If you have freckles, or if your skin reddens or sunburns easily, you're at greater risk for cancer.
5. If you have blonde or red hair, or blue or green eyes, you're more likely to develop skin cancer.
6. If you work or play outdoors, you can reduce your risk of skin cancer by wearing SPF 15+ sunscreen.
7. Tanning beds, booths and sunlamps have been linked to skin cancers including melanoma, therefore, if you have a history of indoor tanning, you're more prone to skin cancer and should see a [dermatologist](#).



Timeliness of Breast Cancer Treatment in Delaware

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Abstract

Studies have shown timely screening, diagnosis, and treatment of breast cancer reduces mortality rates. The objective of this study is to evaluate the overall timeliness of breast cancer diagnosis and treatment for Delawarean women using the Centers for Disease Control and Prevention's (CDC) National Breast and Cervical Cancer Early Detection Program's (NBCCEDP) recommendations of 60 days maximum for screening to diagnosis and 60 days maximum for diagnosis to treatment. This study analyzed Delaware Cancer Registry (DCR) data for female Delawarean breast cancer patients diagnosed in 2010 who had valid screening, diagnosis, and treatment dates. Calculations of three time intervals were performed: screening to diagnosis (Time A), diagnosis to treatment (Time B), and screening to treatment (Time C). The mean and median for Time Intervals A (21.2 days, 17.0 days), B (27.8 days, 25.0 days), and C (49.0 days, 42.0 days) met CDC recommendations. Our results show most Delawarean women who had valid screening, diagnosis, and treatment dates received a diagnosis within 60 days of screening and first course of treatment occurred within 60 days of diagnosis and therefore met the NBCCEDP recommendations.

Introduction

Breast cancer screening followed by timely follow-up and appropriate treatment reduces mortality rates.¹ Studies have shown women who wait longer than 6 to 12 months for diagnostic workup have a poorer prognosis.^{2,3} Limited data is available on how optimal diagnostic and treatment intervals might increase survival time from breast cancer detected by mammography.⁴ Some investigators have found follow-up intervals of up to 3 months may not impact overall survival,⁵ whereas others have shown women who waited more than 30 days for evaluation after breast cancer detection were more likely to experience breast cancer recurrence or death.⁶ The Centers for Disease Control and Prevention (CDC) has established quality standards of having a diagnosis within 60 days of an abnormal screening test result and initiation of treatment within 60 days of diagnosis. These standards ensure timely diagnosis and treatment initiation for women screened through its National Breast and Cervical Cancer Early Detection Program (NBCCEDP).⁷

In Delaware, The Advisory Board Company, a research, technology, and consulting firm, is used to provide standards regarding breast cancer process and outcome standards. These standards include both process benchmarks, in which timeliness of care is outlined, and outcome benchmarks. These benchmarks vary from the NBCCEDP in two ways: time intervals and ideal benchmarks or observed average benchmarks. The Advisory Board Company reports to the National Consortium of Breast Centers, Inc. for timeliness benchmarks. These include an ideal benchmark of fewer than seven calendar days for time from diagnostic mammogram to needle biopsy, an average of 13.9 days for time from diagnostic mammogram to surgical biopsy, and an average of 14.0 days from needle biopsy to initial cancer surgery.⁸ We chose to use the CDC's NBCCEDP standards for this project. While The Advisory Board Company provides timeliness of treatment standards used in the Delaware medical community, one key timeliness benchmark was missing: time from initial screening to diagnosis. Additionally, The Advisory Board Company reports averages and benchmarks for several pathways. Because the reporting and coding within the Delaware Cancer Registry (DCR) is to NAACCR standards, not all of these time periods are defined or captured.

Breast cancer screening rates have risen across the country in recent years.⁹ Reports of an incomplete or delayed clinical follow-up after an abnormal cancer screening may be a significant public health concern.¹⁰ The Delaware Cancer Consortium (DCC) and the Delaware Division of Public Health (DPH) conducted an evaluation to determine if female breast cancer patients were meeting the CDC recommendations regarding time elapsed between screening to diagnosis and diagnosis to treatment initiation. The purpose of this study is to evaluate the overall timeliness of breast cancer care for Delawarean women. Results from this evaluation will enable the DCC to expand future time-to-treatment analyses to include additional diagnosis years and cancer types and serve as a baseline for studying cancer-related time-to-treatment trends statewide.

The DCR is managed by DPH and serves as the state's central cancer registry. Thirty-three facilities submit data to the DCR; these facilities include 7 hospitals, 11 diagnostic laboratories, 15 free-standing ambulatory surgery centers. Dozens of physician offices also submit data to the DCR. The DCR has met the highest rating (Gold certification) given by the North American Association of Central Cancer Registries (NAACCR) for all data years included in this study. Additionally, the DCR is audited by the CDC's National Program of Cancer Registries (NPCR). The most recent audit year was 2008 in which Delaware ranked highest among the eight states audited. The overall data quality was 95.7%, with breast cancer element accuracy rate of 95.5%. In May 2015, The DCR was awarded the 2014 Registry of Excellence by the CDC's NPCR.

Methods

Design and Participants

This study was approved by the Delaware Department of Health and Human Services' Institutional Review Board. This is a cohort study of diagnosed breast cancer patients with a primary residence in Delaware. Patients with breast cancer had to meet the following eligibility criteria to be retained in the analyses: (1) diagnosed with breast cancer during calendar year 2010; (2) female; (3) classified as Class of Case 0, 1, or 2; (4) did not have any signs of breast cancer (i.e. breast lump); and (5) tumor was a primary cancer. The study population used for analyses included 455 cases.

Measures

For this study, the DCR provided complete records for all breast cancer patients diagnosed in the state between January 1, 2010 and December 31, 2010. Breast cancer patients were identified using the Surveillance Epidemiology and End Records (SEER) case definition: ICD-O-3 site C500-509, excluding histologies 9050-9055, 9590-9989, and 9140. For most cancer surveillance activities, a data request is submitted to the DCR to obtain a file of cancer patients and selected variables that would be used for analysis. The DCR fulfills requests by providing an encrypted file but is unable to export text fields using this data exchange method. To facilitate exportation of text fields, the DCR provided a complete NAACCR format file including 534 variables for all breast cancer cases diagnosed in 2010. All variables collected in association with each patient were determined and coded according to NAACCR guidelines.¹¹

Conceptual Model

The conceptual model for this study (Figure 1) was based on the NBCCEDP model and consisted of three time intervals of particular interest (see “A,” “B,” and “C”). Time interval “A” represents the time period between the date a woman receives a mammogram yielding abnormal results and the date of breast cancer diagnosis. Time interval “B” represents the time period between the date a woman receives a diagnosis confirming cancer and the date she begins her cancer treatment. Time interval “C” represents the overall time period between date of abnormal mammogram and date of treatment initiation.

Date Identification for Key Time Interval Variables

Preliminary analyses identified the text fields most often containing key dates of interest. A subset of these text variables was created and each field was manually probed, extracting dates of abnormal screening mammogram, diagnosis, and initiation of treatment. Abnormal screening mammograms had a BI-RADS category of 3 or higher or were described as suspicious or abnormal in the text field of the NAACCR variable “DxProc-XRay/scan.” If there were multiple abnormal screening mammograms, the National Comprehensive Cancer Network (NCCN)

guidelines for Breast Cancer Screening and Diagnosis were followed.¹² All dates were extracted for later analyses and stored in a separate file. This new file was merged with the NAACCR format file, using patient ID as the merging variable. Date of diagnosis was listed as the NAACCR variable “Date of Diagnosis.” Two dates of treatment were described in the NAACCR file: “Date of Initial RX–SEER” and “Date of 1st Crs RX–CoC.” We chose to use “Date of 1st CRS Rx–COC” as the treatment variable in this study because it contained useful information not available in the “Date of Initial RX–SEER” variable. Per the Commission on Cancer (CoC) definition, the date of non-treatment (if applicable) was recorded in this field. In contrast, the SEER-defined variable “Date of Initial RX–SEER” is left blank if no treatment was administered.

Missing Date Data Ascertainment

For cases with a missing screening mammogram date, date of diagnosis, or treatment date described in the text fields or coded within the NAACCR variable, attempts were made to gather these data from the DCR, hospital registries, or the Delaware Health Information Network (DHIN), Delaware’s health information exchange. Three hundred sixteen (316) cases did not have date data available for screening mammogram. All dates were recorded for date of diagnosis and treatment date.

Validation Study

For those cases that did not meet the CDC recommendation of 60 days for time interval “A” or time interval “B,” a validation to determine the reason why the case exceeded recommendations was conducted. This validation was conducted by a three-doctor team and a representative from the Division of Public Health. The physician team consisted of a medical oncologist and two surgical oncologists, one of whom is the medical director of a Delaware cancer center and research institute. The doctors were selected based on expertise and their affiliation with different hospitals, so as to provide a well-balanced and unbiased team for reviewing the various hospital records. The doctors determined if a reason for exceeding CDC recommendations was documented in the patient’s chart and, where a reason was documented, whether or not the reason was acceptable. Cases were classified as either having an

acceptable reason, determined by the clinical expertise of the doctors, or not having an acceptable reason for exceeding CDC recommendations.

Analysis

Analyses were performed for the above-mentioned time intervals. Selected demographic characteristics were summarized using mean and standard deviation for the entire sample, study population, and those ineligible for the study. An independent t-test and chi-square tests were performed to determine if there were statistically significant differences between the study population and those ineligible for the study. These same tests were performed to determine if there were statistically significant differences between those who met recommendations and those who did not meet recommendations. Likewise, analysis using these inferential statistics was used to determine if there were statistically significant differences between those whose chart contained an acceptable reason and those whose chart did not contain an acceptable reason. All analyses were performed using SAS 9.2™ (SAS Institute, Cary, NC).

Results

Baseline characteristics

A total of 937 cases of breast cancer were identified between January 1, 2010 and December 31, 2010. Out of the original sample, 6 were male cases (0.6%) and were excluded from analyses. Further, 13 cases (1.4%) were dropped from the analyses because they were non-analytic cases (i.e. the cases dropped were not Class of Case 0, 1, or 2). One hundred forty-seven cases (15.7%) were not eligible because they were not first primary cases (i.e. the cases dropped had a tumor record number greater than 1). In addition, 316 cases (33.7%) did not have a valid date for at least one abnormal mammogram (Figure 2). All cases had a diagnosis and first course of treatment date. The study population was comprised of 455 breast cancer cases.

Table 1 describes the mean and standard deviation for continuous variables and number and frequency for categorical variables for the entire sample (n=937), study population (n=455), and ineligible cases (n = 482). For the entire sample, the average patient was 62 years old, primarily white (80.5%), from New Castle County (54.9%), had local stage breast cancer

(52.2%), and was either using a private insurance (45.4%) or was on Medicare (44.7%). In the study population, in situ (29.2%) stage cancers were over-represented while regional, distant, and unknown were under-represented. Additionally, all cancers had a stage assigned for those included in the study population. In Table 2, those who met the CDC recommendations and those who did not meet CDC recommendations were compared by demographic characteristics. Those who met CDC recommendations were more likely to be white and have private insurance compared to those who were black and had Medicaid as their insurer. No other differences in county of residence or stage of cancer were observed. Of those who did not meet CDC recommendations, Table 3 compares those who had explanations determined to be acceptable during the validation to those who did not have an acceptable explanation documented in their chart. There were no differences noted for any of the demographic variables.

Statistical Analyses

Univariate analyses were used for descriptive summarization of time intervals, “A,” “B,” and “C.” Baseline characteristics of cases for the conceptual model are shown in Table 1. The mean age at diagnosis was 62 years (range, 27-94 years). Among the 455 cases, the majority of the women were white (80.5%) and lived in New Castle County (54.9%). Most of the women were insured: Private payer (45.4%), Medicare (44.7%), or Medicaid (6.6%). Additionally, the majority of breast cancer cases were in situ (22.4%) or local (52.2%) stage.

Statistical analyses of time intervals

Table 4 summarizes the time intervals for the study population. This table also illustrates the study population whose diagnostic and treatment course met CDC’s recommendations (≤ 60 days) or exceeded recommendations. It is important to note that time interval “C” is the combination of time interval “A” and time interval “B,” both of which independently have a recommendation of ≤ 60 days.

Time interval “A”

For the study population, analysis shows a mean of 21.2 days (median of 17 days) from screening mammogram to first diagnostic procedure. Range

varies from 0 to 322 days. Only 19 cases exceeded the recommended time. Of those within the study population who met the CDC recommendations, it took an average of 18.1 days (median of 16.0 days) from screening mammogram to first diagnostic procedure, compared to those who did not meet the CDC recommendations who took an average of 50.1 days (median 32.5 days). Additional analysis examined those who had explanations determined to be acceptable during the validation compared to those who did not have an acceptable explanation documented in their chart. Of those who were determined to have acceptable explanations documented, the average time to navigate Time A was 56.3 days (median 24.5 days) compared to those who did not have acceptable explanations of 46.5 days (median 36.0 days).

Time interval “B”

Analysis reveals a mean of 27.8 days (median of 25 days) from diagnosis to treatment for the entire sample a range from 0 to 211 days. Only 26 cases exceeded the CDC recommendations during this time interval. Of those within the study population who met CDC recommendations, it took an average of 23.8 days (median 14.5 days) from first diagnostic procedure to first course of treatment compared to those who did not meet CDC recommendations who took an average of 65.4 days (median 62.5 days). Analysis of data collected during the validation revealed that those who had an acceptable documented reason for the delay had an average of 60.1 days (median 65.5 days) compared to those who did not have an acceptable documented reason with an average of 68.4 days (median 62.0 days) to navigate Time B.

Time interval “C”

As noted in Table 4, the mean number of days from screening mammogram to treatment was 49.0 days with a median of 42.0 days; the range was 0 to 322 days. Fifteen cases exceeded recommendations. Those who met the CDC recommendations had an average of 41.9 days (median 40.0 days) from screening mammogram to first course of treatment compared to those who did not meet CDC recommendations with an average of 115.4 days (median 99.5 days). Those with acceptable reasons documented within their charts averaged 116.4 days (median 90.5 days)

compared to an average of 114.9 days (median 102.5 days) for those without acceptable reasons documented within their charts.

Discussion

We chose to use the CDC’s NBCCEDP standards for this project because one key timeliness benchmark was missing from The Advisory Board Company: time from initial screening to diagnosis. In addition, The Advisory Board Company reports averages for several pathways. However, not all of these time periods are captured because data within the DCR are reported and coded to NAACCR standards. The CDC’s NBCCEDP standard recommends a woman receive a diagnosis within 60 days of being screened (Time Interval A). Our study results show a mean of 21.2 days and a median of 17.0 days for women who have had a screening mammography to complete an initial diagnostic procedure. Of the study population, only 19 cases (4.2%) exceeded the recommended 60 days. The CDC also recommends commencement of first course of treatment within 60 days of diagnosis (Time Interval B). Our study shows a mean of 27.8 days with a median of 25.0 days for this time interval. Only 26 (5.7%) women exceeded this recommendation. Additionally, for the entire time interval investigated (screening to first course of treatment, aka Time Interval C), only 15 women (3.3%) exceeded 120 days.

Of those who exceeded the CDC recommendations, a validation study was conducted to determine if the patient’s chart included an acceptable reason for a delay in care for that particular time interval. Of the 44 total patients exceeding CDC recommendations, 28 (63.6%) charts did not contain an acceptable reason. Reasons were evaluated based on the expertise of the three-doctor validation team. A variety of reasons were found to be acceptable, including taking time to receive a second opinion, illness of a spouse, patient scheduling issues, and patient did not follow up despite provider effort to contact the patient. Many charts did not contain an explanation for the delay in care and therefore, were automatically deemed unacceptable. Of those charts with an unacceptable explanation, the most common reason included provider coordination and scheduling of multiple procedures.

Limitations and Strengths

Our study was specifically designed as an evaluation project to determine the average length of time between screening, diagnosis, and treatment initiation among Delaware women diagnosed with breast cancer. Because of the length of time that has elapsed since the 2010 diagnoses, our results may not reflect current practices.

Our study population also included only those who had a valid screening procedure date, diagnosis date, and treatment initiation date. Therefore, the study population included only 59.0% of the eligible sample. When the study population was compared to the excluded cases, differences in age, stage of cancer, and primary payer were noted. These differences could have created bias in our study population. A number of variables of interest are not collected by DCR as they are not required by NAACCR. A key variable, screening date, was manually abstracted from text fields. When multiple mammography dates were found, the NCCN Guidelines Breast Cancer Screening and Diagnosis were used to determine the clinically significant mammogram. However, dates related to screening are not required variables within the NAACCR dataset. Therefore, while many observations had dates provided within text variables, some observations were missing screening dates completely. DCR only requires dates of diagnosis and first course of treatment, not dates of specific procedures. Therefore, analyzing timeliness between specific procedures is not feasible without manually extracting dates from charts. Some hospitals choose to follow the Advisory Board Company guidelines providing stricter, shorter time frames for periods between procedures. This practice may enhance the timeliness of breast cancer care within the organization. However, at this time, due to the incompatibility of DCR variable capture and Advisory Board Company guideline variables, we are unable to evaluate these timeliness benchmarks. Recommendations may be made that the DCR consider adopting additional variables which align with other guidelines and help facilitate further analyses.

The only variable available to indicate socioeconomic status (SES) was primary payer. Due to the average age of our study population, Medicare, which is not indicative of SES, was the insurance payer for over

40% of our study population. Therefore, in future studies, methodology to calculate SES should be included so this social indicator can be used in analyses and controlled for in any multivariate analyses. Only a small portion (6.2%) of the study population failed to meet the CDC recommendations and deemed unacceptable. However, the goal is to have no cases outside of the CDC recommendations and deemed unacceptable. The CDC guidelines are meant to be a maximum length of time between dates and therefore, should not be exceeded without an acceptable reason. The majority of cases where a reason was documented – but deemed unacceptable - appeared to involve poor organization. Future cases such as these could be avoided by more fully utilizing the services provided under the cancer screening nurse navigator housed within each hospital. The nurse navigator is responsible for assisting a woman through the screening process until a diagnosis is reached. This service is available to any Delaware resident being screened for cancer. However, because most cases were deemed unacceptable due to the lack of documentation within the chart, providers need to take greater care in documenting reasons for delays. In follow up studies, we would like to investigate these timeliness of treatment benchmarks with a larger sample size. Because Delaware has a small population, it may be necessary to look at these benchmarks across several years to create a larger sample. We would also like to explore the possibility of benchmarking timeliness of treatment to the Advisory Board Company guidelines.

Conclusions

The DCR is an important source of data for investigating cancer and cancer treatment trends in Delaware. Our results show most Delawarean women who had valid date data received a diagnosis within 60 days of screening, and first course of treatment occurred within 60 days of diagnosis. However, further investigation needs to be conducted with a larger population. Additional benchmarks, such as those provided by the Advisory Board Company with shorter times between procedures, should be investigated. Bias may have been created due to the sampling methods which eliminated a large proportion (41.0%) of the eligible sample due to missing dates. In summary, this study has shown most Delawarean women who had valid date data received a

diagnosis within 60 days of screening, and first course of treatment occurred within 60 days of diagnosis. Identifying disparities in race, ethnicity, or socioeconomic status may be important to identify at-risk populations, which can then be identified for targeted public health interventions. Additionally, future research needs to focus on identifying the barriers to follow-up so effective interventions may be implemented.

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Figure 1. Conceptual Model

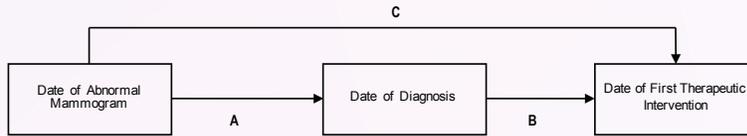


Figure 2. Inclusion Criteria Flow Diagram

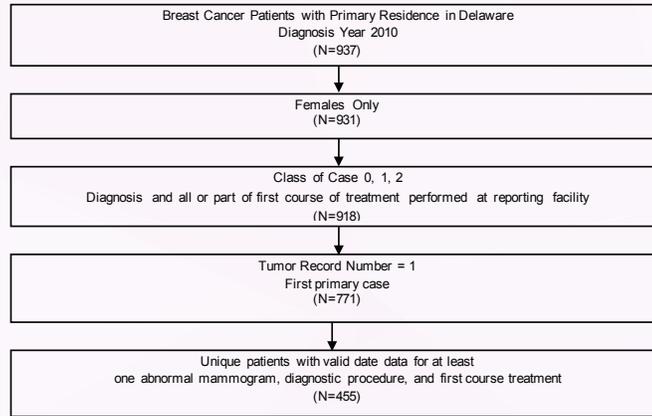


Table 1. Comparison of the cases included in the study population to those who were excluded.

Variable	Entire Sample	Study Population	Ineligible from Study Population	Independent t - test (p-value)
	n = 937	n = 455	n = 482	
Age	Mean (SD) 62.3 (13.6)	Mean (SD) 61.3 (12.7)	Mean (SD) 63.2 (14.3)	-2.06 (.0400)*
Race				χ^2 (p-value) 0.9746 (.6143)
White	754 (80.5)	364 (80.0)	390 (80.9)	6.8961 (.0318)*
Black	163 (17.4)	83 (18.2)	80 (16.6)	
Other	20 (2.1)	8 (1.8)	12 (2.5)	
County				48.1976 (<.0001)*
Kent	190 (20.3)	84 (18.5)	106 (22.0)	
New Castle	514 (54.9)	241 (53.0)	273 (56.6)	
Sussex	233 (24.9)	130 (28.6)	103 (21.4)	
Stage				10.1716 (.0376)*
In situ	210 (22.4)	133 (29.2)	77 (16.0)	
Local	489 (52.2)	245 (53.9)	244 (50.6)	
Regional	194 (20.7)	69 (15.2)	125 (25.9)	
Distant	34 (3.6)	5 (1.3)	28 (5.8)	
Unknown	10 (1.1)	2 (0.4)	8 (1.7)	
Primary Payer				
Not Insured	9 (1.0)	3 (0.6)	6 (1.2)	10.1716 (.0376)*
Private	425 (45.4)	223 (49.0)	202 (41.9)	
Medicaid	62 (6.6)	30 (6.6)	32 (6.6)	
Medicare	419 (44.7)	194 (42.6)	225 (46.7)	
Unknown	22 (2.4)	5 (1.1)	17 (3.5)	

*p-value <0.05

Table 2. Comparison of the included cases in the study population that met CDC recommendations to those who did not meet CDC recommendations.

Variable	Study Population	Met CDC recommendations	Did not meet CDC recommendations	Independent t - test (p-value)
	n = 455	n = 411	n = 44	
Age	Mean (SD) 61.3 (12.7)	Mean (SD) 61.4 (12.8)	Mean (SD) 60.9 (12.7)	0.23 (.8221)
Race				χ^2 (p-value) 13.8 (.0010)*
White	364 (80.0)	338 (82.2)	26 (59.1)	3.5653 (.1682)
Black	83 (18.2)	66 (16.1)	17 (38.6)	
Other	8 (1.8)	7 (1.7)	1 (2.3)	
County				7.7402 (.1016)
Kent	84 (18.5)	72 (17.5)	12 (27.3)	
New Castle	241 (53.0)	223 (54.3)	18 (40.9)	
Sussex	130 (28.6)	116 (28.2)	14 (31.8)	
Stage				11.5 (.0218)*
In situ	133 (29.2)	115 (28.0)	18 (40.9)	
Local	245 (53.9)	225 (54.7)	20 (45.5)	
Regional	69 (15.2)	64 (15.6)	5 (11.4)	
Distant	5 (1.3)	6 (1.5)	0 (0.0)	
Unknown	2 (0.4)	1 (0.2)	1 (2.3)	
Primary Payer				
Not Insured	3 (0.6)	3 (0.7)	0 (0.0)	11.5 (.0218)*
Private	223 (49.0)	205 (49.9)	18 (40.9)	
Medicaid	30 (6.6)	22 (5.4)	8 (18.2)	
Medicare	194 (42.6)	176 (42.8)	18 (40.9)	
Unknown	5 (1.1)	5 (1.2)	0 (0.0)	

*p-value <0.05

Table 3. Comparison of those who did not meet CDC recommendations by chart containing or not containing an acceptable reason for exceeding recommendation.

Variable	Did not meet CDC Recommendations	Chart contained acceptable reason	Chart did not contain an acceptable reason	Independent t - test (p-value)
	n = 44	n = 16	n = 28	
Age	Mean (SD) 60.9 (12.7)	Mean (SD) 62.2 (14.0)	Mean (SD) 60.2 (12.0)	0.49 (.6245)
Race				χ^2 (p-value) 0.7759 (.6784)
White	26 (59.1)	8 (56.3)	17 (60.7)	0.9743 (.6144)
Black	17 (38.6)	7 (43.8)	10 (35.7)	
Other	1 (2.3)	0 (0.0)	1 (3.8)	
County				2.4663 (.4814)
Kent	12 (27.3)	3 (18.8)	9 (32.1)	
New Castle	18 (40.9)	7 (43.8)	11 (39.3)	
Sussex	14 (31.8)	6 (37.5)	8 (28.6)	
Stage				0.1255 (.9392)
In situ	18 (40.9)	5 (31.3)	13 (46.4)	
Local	20 (45.5)	8 (50.0)	12 (42.9)	
Regional	5 (11.4)	3 (18.8)	2 (7.1)	
Distant	0 (0.0)	0 (0.0)	0 (0.0)	
Unknown	1 (2.3)	0 (0.0)	1 (3.6)	
Primary Payer				
Not Insured	0 (0.0)	0 (0.0)	0 (0.0)	0.1255 (.9392)
Private	18 (40.9)	6 (37.5)	12 (42.9)	
Medicaid	8 (18.2)	3 (18.8)	5 (17.9)	
Medicare	18 (40.9)	7 (43.8)	11 (39.3)	
Unknown	0 (0.0)	0 (0.0)	0 (0.0)	

*p-value <0.05

Table 4. Comparison of Time Interval A, B, and C for the Study Population, Met CDC Recommendations, and Did Not Meet CDC recommendations.

Time Interval	Mean (SD)	Median (Q1, Q3)	IQR	Range (Min, Max)
Time A				
Study Population	21.2 (24.5)	17.0 (6.0, 28.0)	22.0	322.0 (0.0, 322.0)
Met	18.1 (14.9)	16.0 (6.0, 27.0)	21.0	59.0 (0.0, 59.0)
Recommendations				
Did not meet	50.1 (57.5)	32.5 (13.5, 71.5)	58.0	322.0 (0.0, 322.0)
Recommendations				
Acceptable	56.3 (79.4)	24.5 (8.5, 76.0)	67.5	322.0 (0.0, 322.0)
Unacceptable	46.5 (41.6)	36.0 (19.0, 68.5)	49.5	192.0 (0.0, 192.0)
Time B				
Study Population	27.8 (24.1)	25.0 (15.0, 35.0)	20.0	211.0 (0.0, 211.0)
Met	23.8 (14.5)	23.0 (15.0, 32.0)	17.0	60.0 (0.0, 60.0)
Recommendations				
Did not meet	65.4 (50.5)	62.5 (25.5, 82.0)	56.5	211.0 (0.0, 211.0)
Recommendations				
Acceptable	60.1 (55.7)	65.5 (0.0, 89.0)	89.0	49.0 (0.0, 168.0)
Unacceptable	68.4 (48.0)	62.0 (37.5, 80.5)	43.0	211.0 (0.0, 211.0)
Time C				
Study Population	49.0 (32.6)	42.0 (29.0, 62.0)	33.0	321.0 (1.0, 322.0)
Met	41.9 (19.3)	40.0 (28.0, 54.0)	26.0	106.0 (1.0, 107.0)
Recommendations				
Did not meet	115.4 (51.6)	99.5 (85.0, 124.0)	39.0	260.0 (62.0, 322.0)
Recommendations				
Acceptable	116.4 (66.3)	90.5 (73.5, 128.5)	55.0	259.0 (62.0, 322.0)
Unacceptable	114.9 (42.5)	102.5 (86.0, 122.5)	36.5	171.0 (62.0, 233.0)

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Screening for Prostate Cancer:

Making Sense of the US Preventive Services Task Force 2017 Draft Recommendation Statement

David M. Bercan, M.D.

In April, 2017, the United States Preventive Service Task Force (USPSTF) issued a draft recommendation statement on screening for prostate cancer.¹ This draft recommendation reflects an update of the 2012 recommendations.² This article will examine the proposed changes in the new recommendations, the rationale behind the changes, and offer guidance for their implementation by practicing clinicians.

Background

The Centers for Disease Control and Prevention estimates that more than 2.5 million US men were diagnosed and living with prostate cancer in 2013.³ During that same year, 176,000 US men were diagnosed with prostate cancer, and nearly 28,000 died from prostate cancer.⁴ Most men with prostate cancer are asymptomatic. Autopsy studies of men who died from other causes have demonstrated greater than 20% incidence in men 50-59 years of age, and greater than 30% of men 75 years of age and older.⁵ However, prostate cancer may be both symptomatic and aggressive, accounting for the death in 25,000 men in 2016.³ Ideally, screening for prostate cancer should identify early, localized disease which is high-risk and

can be successfully treated to prevent morbidity and mortality from metastatic disease.

Measurement of the level of prostate-specific antigen (PSA) is the most common form of screening for prostate cancer. Elevations of PSA can occur in prostate cancer, but elevations may also occur as false positives—usually from benign prostatic hyperplasia or prostatitis. Diagnosis of prostate cancer relies upon an invasive procedure, transrectal ultrasound-guided core-needle biopsy. Currently there is no definitive method for distinguishing between those prostate cancers which will become progressive and/or metastatic and those which will remain indolent and asymptomatic.

2012 USPSTF Recommendations

In 2012, the USPSTF recommended against PSA-based screening for prostate cancer, giving it a grade D recommendation (“There is moderate or high certainty that the service has no net benefit or that the harms outweigh the benefits.”).² The 2012 recommendations were based largely upon two major trials of PSA screening: the U.S. Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial (PLCO) and the

European Randomized Study of Screening for Prostate Cancer (ERSPC). The U.S. trial failed to demonstrate reduction in prostate cancer mortality,⁶ while the European trial demonstrated a reduction in prostate cancer deaths of approximately 1 death per 1000 men screened in the 55 to 69 year old subgroup.⁷

In the 2012 recommendations, the USPSTF considered the potential harms related to screening for prostate cancer. They cited the high incidence of false positive PSA results (approximately 80% when cutoffs between 2.5 and 4.0 µg/L are used).⁷ False positive results may cause unnecessary negative psychological impact as well as unnecessary invasive procedures such as prostate biopsy. One third of men who undergo prostate biopsy report having to seek follow-up care for significant pain, fever, hematuria, UTI, or transient dysuria or hesitancy.⁸

The 2012 USPSTF recommendations also considered the potential harm related to treating prostate cancer detected by PSA screening. Approximately 3 to 5 in 1000 men who undergo prostate cancer surgery will die within 1 month of the procedure, and between 10 and 70 men in 1000 will have serious post-operative complications requiring intervention. Between 200 and 300 in 1000 post-prostatectomy men will experience long-term urinary incontinence and/or erectile dysfunction.^{9,10} Radical prostatectomy is associated with a 20% incidence of long-term urinary incontinence requiring regular use of pads, and with long-term erectile dysfunction in two out of three men.^{9,10} Radiation therapy is associated with long-term erectile dysfunction in more than half of subjects, and with bothersome bowel symptoms (bowel urgency and fecal incontinence) in one out of six men. Androgen deprivation therapy is associated with a 40% incidence of erectile dysfunction, and has not demonstrated improved survival in localized prostate cancer.^{9,10}

Additionally, the recommendations noted that substantial overdiagnosis of prostate cancer will identify men who would have had an indolent form of cancer which would never have caused symptoms and would not have contributed to their death. Since our ability to distinguish indolent cancers from aggressive cancers is modest, at best, many of these men will elect to undergo unnecessary treatment.

The USPSTF concluded in 2012 that "...there is convincing evidence that PSA-based screening for prostate cancer results in considerable overtreatment and its associated harms."² The USPSTF concluded that "there is moderate certainty that the benefits of PSA-based screening for prostate cancer do not outweigh the harms."²

2017 USPSTF Draft Recommendations

The proposed summary statement regarding screening for prostate cancer reads:

The decision about whether to be screened for prostate cancer should be an individual one. The USPSTF recommends that clinicians inform men ages 55 to 69 years about the potential benefits and harms of PSA-based screening for prostate cancer. Screening offers a small potential benefit of reducing the chance of dying of prostate cancer. However, many men will experience potential harms of screening, including false-positive results that require additional testing and possible prostate biopsy; overdiagnosis and overtreatment; and treatment complications, such as incontinence and impotence. The USPSTF recommends individualized decision-making about screening for prostate cancer after discussion with a clinician, so that each man has an opportunity to understand the potential benefits and harms of screening and to incorporate his values and preferences into his decision. (C recommendation: "Clinicians may provide this service to selected patients depending on individual circumstances. However, for most persons without signs or symptoms there is likely to be only a small benefit from this service.")¹

The change from a D to a C recommendation is based upon additional studies which have been published since the 2012 recommendations. Three factors are largely responsible for the USPSTF recommendations change:

- The largest ongoing trial to demonstrate the benefit of screening (ERSPC), published the results of 13 years of follow-up in Lancet in 2014. The study demonstrated an ongoing reduction in prostate cancer mortality of slightly more than one man per 1000 screened (RR, 0.79 [95% CI, 0.69-0.91]).¹¹

- ERSPC offered additional new data suggesting that 3.1 men per 1000 screened would avoid metastatic prostate cancer (RR, 0.70 [95% CI, 0.60-0.82]).¹²
- There has been a significant increase in “active surveillance” since the 2012 recommendations, allaying some of the previous concerns about the harms of screening. Active surveillance offers men with a lower-risk prostate cancer (based upon clinical stage, tumor grade, and PSA level) the option of monitoring, via more frequent PSA testing and/or repeat biopsy, rather than proceeding directly to treatment interventions. Under this approach, treatment can be reserved for those men whose cancer appears to be progressing while under surveillance. Cooperberg and Carroll documented that in the United States, active surveillance increased from a rate of about 10% of men diagnosed with lower-risk prostate cancer from 2005-2009, to a rate of about 40% from 2010-2013.¹³ The USPSTF acknowledged that more longer-term followup studies are needed in order to assure that active surveillance in this select population is as effective as intervention with radiation and/or surgery, since one study has reported an increase in metastatic disease compared to the intervention group.¹

The USPSTF 2017 draft recommendation concludes, with moderate certainty, that:

...overall, the potential benefits and harms of PSA-based screening for prostate cancer in men ages 55-69 years are closely balanced. Each man's individual values and preferences will determine whether he feels that the overall balance of potential benefits and harms is positive or negative.¹

The USPSTF 2017 draft recommendations again advise clinicians about the potential harms of overdiagnosis (identifying asymptomatic cancers which would never have contributed to death). In addition to causing unnecessary anxiety over a diagnosis of prostate cancer, overdiagnosis exposes men to unnecessary active surveillance (with repeat PSA measurements and possible repeat prostate biopsies) and/or unnecessary treatment (surgery, radiation, and/or antiandrogen therapy). While it is impossible to conclusively determine the overdiagnosis rate, decision analysis models suggest that 21% of screen-detected cancers in the PLCO trial and 50% in the ERSPC trial were overdiagnosed.¹⁴

The USPSTF 2017 draft recommendation acknowledges that there are two groups of men who are underrepresented in the prostate cancer screening trials: African American men and men who have a family history of prostate cancer.

Regarding African American men:

- Despite the 12.6% African American makeup of the US population, only 4% of the participants in the PLCO trial were African American.
- Unfortunately, African American males have double the incidence of prostate cancer compared with white men (203.5 vs. 121.9 cases per 100,000 men).³ They are also more likely to die of prostate cancer (44.1 vs. 19.1 deaths per 100,000 men).³
- One caveat which the USPSTF offers (which is not based upon randomized controlled trials, but upon decision analysis models) is that given the higher rates of aggressive prostate cancer in African American men, PSA-based screening may provide greater benefit to African American men than the general population.³
- Until further studies suggest otherwise, the USPSTF advises that there is insufficient evidence to guide more specific screening recommendations for African American men, so this group has also been included in the C recommendation.¹

Regarding men with a family history of prostate cancer:

- Data from the Finnish arm of the ERSPC trial suggest that men with a first degree relative with prostate cancer are 30% more likely to be diagnosed with prostate cancer than men without a family history.¹⁵
- The PLCO trial included 7% of its subjects reporting a family history of prostate cancer. This subset had a lower rate of prostate cancer-specific mortality when screened with PSA compared with controls, but the difference was not statistically significant and may have been under-powered (hazard ratio, 0.49 [95% CI, 0.22 to 1.10]; p = 0.08).¹⁶
- Screening may increase the potential for harm, especially among men with a family history of indolent and less aggressive prostate cancers.¹
- Until further studies suggest otherwise, the USPSTF

advises that there is insufficient evidence to guide more specific screening recommendations for men with a family history of prostate cancer, so this group has also been included in the C recommendation.¹

The USPSTF draft recommendations did not revise their 2012 recommendations regarding men 70 years and older:

- The USPSTF has retained its previous D recommendation for its proposed guidelines. There is adequate evidence from randomized controlled trials demonstrating no mortality benefit for men in this age group.¹

The Way Forward: Implementing the proposed 2017 guidelines

The newly proposed C recommendation from the USPSTF emphasizes that “the balance of benefits and harms in men remains close,” so the decision to screen for prostate cancer in men ages 55 to 69 years of age must be individualized.¹ This shared decision-making model requires clinicians to educate their patients about the potential benefits and harms of screening, and then base the mutual decision upon the patient’s individual values and preferences.

Some men may value finding and treating prostate cancer so highly that they are readily willing to assume the risks of prostate biopsy, radiation therapy, surgery, and/or androgen deprivation therapy—if those interventions will provide the highest level of assurance that they will not suffer from the morbidity or mortality of metastatic prostate cancer. Others may be more comfortable not being screened, given the very close balance of benefit versus harm. It is likely that a majority of men (and their clinicians) will struggle with the decision, knowing that the body of knowledge is incomplete, that the net benefit is small, and that the interventions have the potential to cause more harm than good.

To make an informed decision about prostate cancer screening, men must be informed about the risks of overdiagnosis and overtreatment. Clinicians should emphasize that ordering a PSA test is not “just a blood test.” If the PSA result is a true positive, having ordered that test was a potential invitation to prevent morbidity and mortality from prostate cancer—yet at the same time, is also an invitation to unintended morbidity

and mortality from overdiagnosis and overtreatment. If the PSA result is a false positive, having ordered that test was an invitation to unnecessary anxiety, further invasive testing (including prostate biopsy), and unnecessary repeat PSA screening (possibly leading to repeat biopsies).

A meaningful discussion with a patient about screening for prostate cancer includes not only informing them about the pros and cons of PSA testing, but also delving into that patient’s personal values and preferences. This discussion typically occurs during a busy office visit which also focuses upon acute and/or chronic illnesses, other preventive health concerns, and the myriad of quality metrics which must be addressed. Doing justice to the commitment to a quality discussion about shared decision-making is a potentially daunting task.

As is often the case with medical evidence, we have access to improved guidelines based on new and better information. The USPSTF has provided professional (see Appendix A)¹ and patient education material (see Appendix B)¹ to assist the clinician in this endeavor. There is still no ‘one size fits all’ approach; primary care providers and specialists will need ongoing partnership with their shared patients to make optimal decisions.

Appendix A:

Draft: Table. Estimated Effects After 13 Years of Inviting U.S. Men Ages 55 to 69 Years to PSA-Based Screening for Prostate Cancer*

	Number of Men Affected
Men invited to screening	1,000
Men who receive at least 1 positive PSA test result	240
Men who have 1 or more transrectal prostate biopsies	220 [†]
Men hospitalized for a biopsy complication	2
Men diagnosed with prostate cancer	100
Men who initially receive active treatment with radical prostatectomy or radiation therapy	65
Men who initially receive active surveillance	30
Men who initially receive active surveillance who go on to receive active treatment with radical prostatectomy or radiation therapy	15
Men with sexual dysfunction who received initial or deferred treatment	60
Men with urinary incontinence who received initial or deferred treatment	15
Men who avoid metastatic prostate cancer	3
Men who die of causes other than prostate cancer	200
Men who die of prostate cancer despite screening, diagnosis, and treatment	5
Men who avoid dying of prostate cancer	1 to 2

*Estimates based on benefits observed in the ERSPC trial for men ages 55 to 69 years.

[†]Result based on biopsy rate in the ERSPC trial. Current practice in the United States will likely result in fewer biopsies. The potential effect of fewer biopsies on other outcomes, including reductions in prostate cancer diagnosis and mortality, are not clear.

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Partners in Research: Developing a Patient-Centered Research Agenda for Chronic Kidney Disease (CKD)

PLEASE SAVE THE DATE



DATE: Friday, September 15th

TIME: 8:00 am to 1:00 pm
(Registration opens at 7:30 am)

**LOCATION: John H. Ammon Medical Education Center
at Christiana Hospital.**

REGISTRATION WILL OPEN MID-JULY

Chronic Kidney Disease (CKD) and end stage renal disease (ESRD) are serious and costly diseases. CKD affects more than 20 million adults, and is seen most often in individuals over 60 years of age. Diabetes and hypertension are the most frequent causes of CKD in the United States.

We invite you to attend our second conference which is part of a two-year project to engage stakeholders as we address the impact and burden of CKD and ESRD in Delaware. Patients and their supporters, providers, payers, researchers, and policy makers are all encouraged to attend this event.

Please join us as we work together to address CKD and ESRD. Together, we will make a difference.

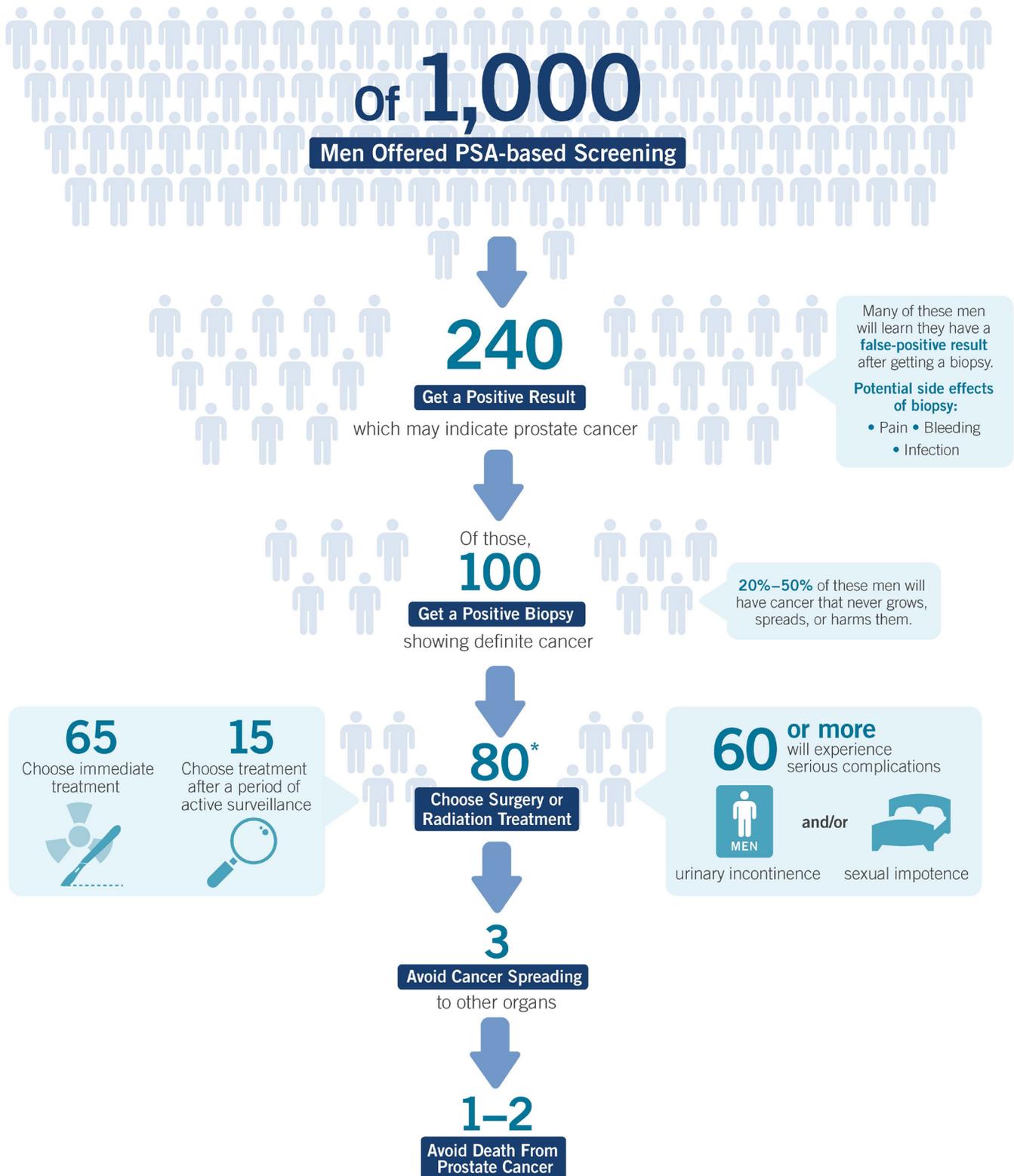


Is Prostate Cancer Screening Right for You?

Understanding the Potential Benefits vs. Risks for Men 55 and Older

The prostate-specific antigen (PSA) screening test is the most common method clinicians use to screen for prostate cancer. The PSA test measures the amount of PSA, a type of protein, in the blood. When a man has an elevated PSA level, it may be caused by prostate cancer, but it could also be caused by other conditions too.

Studies show that PSA-based screening in men 55–69 comes with potential benefits and harms over a period of 10–15 years.





Community View Psychosocial Care for People with Cancer: The Cancer Support Community Model

*Sean M. Hebbel, LCSW, OSW-C
Program Director, Cancer Support Community Delaware*

In 2007 the Institute of Medicine released “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs.” The report lent credence to what Cancer Support Community had been saying since its inception as The Wellness Community in California in 1982 – that the psychosocial and emotional needs of people with cancer should be addressed along with the physical needs in order to treat the whole person. In 1982, successful Beverly Hills and NYC based real estate attorney, Harold Benjamin was searching for emotional support for he and his wife Harriett who had just been diagnosed with breast cancer. He found limited support in the community through the cancer advocacy organizations that offered support groups usually in a church or community center; sometimes as a self-help group and sometimes professionally facilitated. He also found the hospitals would provide support in the hospital setting however he wanted to avoid going into the hospital. His idea, novel in 1982, was that there should be a warm, inviting, and comfortable place away from hospitals where people with cancer and their loved ones could focus on the emotional recovery of the many psychosocial issues that being diagnosed and treated for cancer brought to the table. With his own money he purchased a “little yellow house” in Santa Monica and enlisted several licensed mental health practitioners to devise a program for the complete psychosocial care of people with cancer and their caregivers. He named it The

Wellness Community with the idea that people would be well despite cancer. The program that was developed in 1982 remains relatively unchanged today: weekly support groups for people in active treatment (defined as within 18 months of any kind of treatment for any kind of cancer) monthly support groups for specific cancers, educational programs to help people learn how to be their own advocate, and healthy lifestyle programs to deal with the stressors of cancer; like yoga, t'ai chi, mindfulness based stress reduction, etc. All programs were to be facilitated by licensed and specialty trained mental health clinicians or trained instructors and specialists in their field. The services were to be offered to anyone at no-cost to the participant, caregiver, and family member; no insurance cards and no co-pays. Due to the location's close proximity



to the movie and entertainment industry many high profile people with cancer enjoyed services at The Wellness Community in Santa Monica. One person, Gilda Radner, an original Saturday Night Live performer used The Wellness Community in her very public bout with ovarian cancer. Many people heard of and participated in the programs, and wanted one in their community. In Delaware, two women Ellen Hamilton and Cindy Dwyer were looking for a way to find support for their own cancer experiences but also to support a good friend Mary Moller who was battling ovarian cancer. Hamilton and Dwyer contacted founder Harold Benjamin and after three years of planning, The Wellness Community Delaware (name later changed to Cancer Support Community Delaware) began offering services in a loaned office near Trolley Square in April of 1996. With corporate and foundation support, the help of many individuals, and grants from the Delaware Health Fund and the State of Delaware, Cancer Support Community Delaware now provides our services statewide in three homelike locations in New Castle, Kent and Sussex counties, with a small satellite location recently opened in Middletown.

Cancer is an illness with many facets: physical, emotional, existential and spiritual. All of these facets are incorporated into the support program discussions. The weekly groups are comprised of people with cancer which are currently or recently in active treatment. The isolation that people can feel when diagnosed and treated for cancer, despite having excellent family, friend and faith support is impacted when everyone in the room has heard the words “you have cancer.” People with cancer are sometimes surprised that the people they thought would be supportive of them either cannot or will not for various reasons but, sometimes, complete strangers step up and become important supporters during the cancer experience. Frequently these are members of a support group. Another key psychological issue after cancer is the loss of control the illness can bring. The word “cancer” can challenge our existence. “Will I survive this?” is often an early thought after diagnosis no matter how favorable the statistics. Death can be perceived as the ultimate loss of control and in our present society; discussions of death and even expressing feeling about death can be discouraged. The groups provide a safe place where people can go to express this and many other concerns with folks

who understand and share similar feelings. Cancer treatment can generate feelings of being out of control throughout the process. Once in the care of the health professionals it is easy to lose sight of your own identity; from the hospital bracelet to the sometimes difficult treatments self-image can change. When these feelings are discussed within the group context a sense of control can return. Finally there is the question of hope. Even people with late stage cancers can find hope; if not of being cured, then of comfort and improved quality of life. Hope is not the same as being positive. While it is nice to be able to maintain a positive outlook there can be some difficult moments during cancer treatment that positivity might not help-maintaining hope, however, might.

In addition to the emotional concerns addressed by CSCDE, more research is indicating that effectively coping with stress and remaining as physically active as possible can improve outcomes and certainly impact quality of life. With that in mind, Cancer Support Community Delaware offers multiple physical activities and stress reducing programs: yoga, t'ai chi, mindfulness based stress reduction, as well as writing, art and poetry classes to compliment the emotional support. Social events such as movie nights and pot luck lunches can also help folks deal with the isolation of being treated for cancer. Another important aspect of the program is the use of art/music/movement in helping people better deal with or even reframe some of their emotional concerns about cancer. Of course, not everyone survives cancer and we have two important bereavement programs; Living with Loss is a six session program that discusses normal grieving



and gives people support in the first few months after the death of a loved one; The Next Step addresses the needs of those who are a year or so after the loss and still desire to meet with others who are dealing with longer term bereavement issues. The idea is for all of the programs to give those with cancer and their caregivers a safe place to discuss anything that can improve their quality of life, the opportunity of meeting others who are struggling with similar issues and mechanisms to cancer survivorship. Here are some thoughts participants shared about Cancer Support Community Delaware:

“My support group has become my second family.”

“The staff has made the group, from day one, a place to feel free to express whatever we needed to and have given us an outlet to figure out how to move forward. The weekly groups consist of multiple types of cancer which allows us to hear very different points of view which can help our level of understanding.”

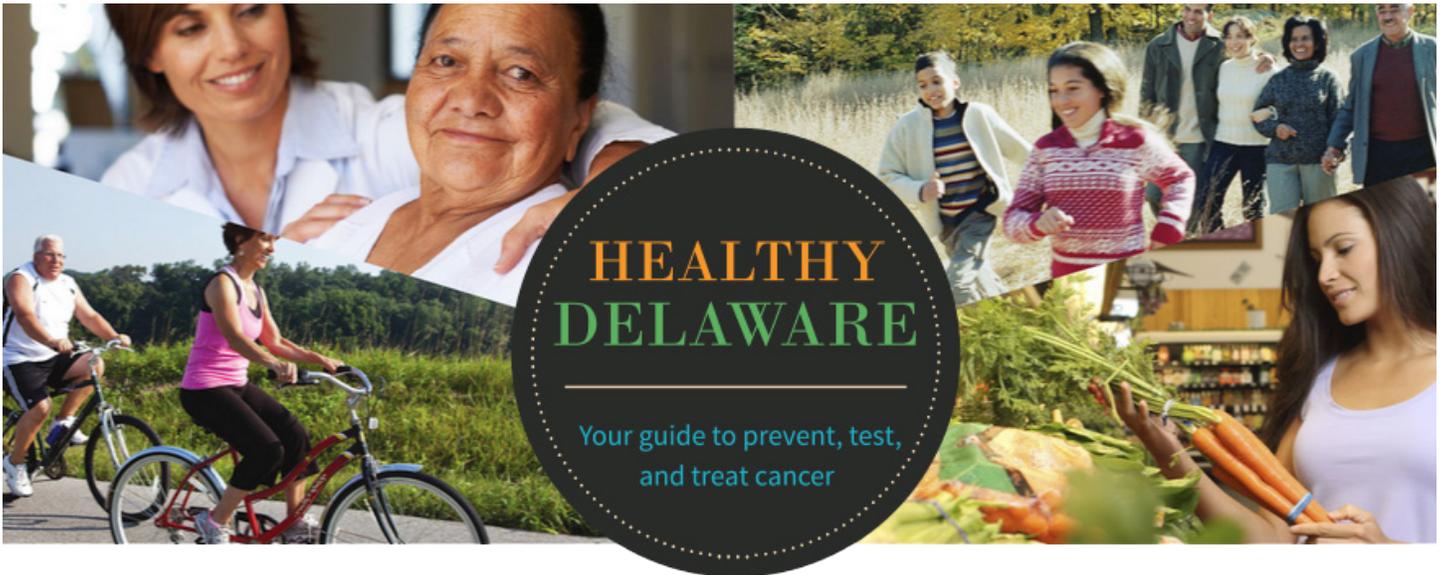
“I gain a safe place to speak about what we are going through without judgment. I feel support and try and give support to others which also helps me. I’m glad my husband has his own group to talk about what he is going through.”



Sean M. Hebbel has been the Program Director at Cancer Support Community Delaware since 1996. He has been a licensed clinical social worker since 1983 with experience working in regional medical centers, university based health systems and community health organizations Hebbel has previously served as Board President of the Board of Social Work Examiners for the State of Delaware and Clinical Social Work Society of Delaware, past Chair of the National Certification Board of the Association of Oncology Social Work, and past Treasurer for the Association of Oncology Social Work. He serves on the Quality Care Committee of the Delaware Cancer Consortium and the Patient Services Committee of the Leukemia and Lymphoma Society.

Cancer Support Community was founded for one reason: to give people with cancer and their loved ones a safe place to do whatever they need to do to gain support during their most isolating experience. Our hope is that we provide a doorway into complete cancer survivorship. We define a cancer survivor as “anyone who has heard the word ‘you have cancer’ and is still breathing”. Many people are so overwhelmed with the physical details of cancer treatment that they do not experience some of the emotional side effects until active treatment ends. While we are here for people during all phases of treatment, most of our participants come to us as active treatment is ending. Because of the advances in the diagnosis and treatment of cancer there are approximately 13 million cancer survivors in the United States at the present time. As the treatment for many cancers is becoming more like a “chronic illnesses” the need for support continues to grow. There are predictions of up to 18 million cancer survivors by 2025. Please remember to recommend our high quality emotional support programs to those who are in active treatment and beyond.





Honor and celebrate cancer survivorship.

Thanks to advances in cancer prevention, early detection, treatment, and follow-up care, cancer survivors are living longer after diagnosis. In fact, as of January 1, 2016, there were 50,760 cancer survivors in Delaware [1], and nearly 14 million Americans who have been diagnosed with cancer are living in the U.S. [2] **Sunday, June 4th** was National Cancer Survivors Day. This is a day to honor cancer survivors, recognize their challenges, and most importantly, celebrate life.

Life after cancer can be rewarding and inspiring. However, the effects of being diagnosed with cancer do not necessarily end when treatment does. Survivors may face emotional, physical, and financial struggles, as well as the fear of cancer recurrence. Challenges such as denial of health insurance and life insurance coverage, difficulty finding jobs, and economic burdens due to mounting medical expenses, lost wages, and reduced productivity are just some of the [challenges cancer survivors may face](#). Cancer survivors are also at greater risk for developing second cancers and other health conditions.



As a community, so many have been touched by cancer in some way and it is essential we know how important ensuring a good quality of life is for cancer survivors. Family, friends, and caregivers, spread the word with **#NCSD2017** and join us as we celebrate cancer survivors around the world.

[Read survivors' words of wisdom.](#)

[1] American Cancer Society. <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-treatment-and-survivorship-facts-and-figures/cancer-treatment-and-survivorship-facts-and-figures-2016-2017.pdf>

[2] Centers for Disease Control and Prevention. Basic Information for Cancer Survivors. https://www.cdc.gov/cancer/survivorship/basic_info/survivors/index.htm

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The Delaware Cancer Treatment Program (DCTP) is a program intended to provide medical insurance coverage to uninsured Delawareans for the treatment of cancer. It is operated by the Health Promotion and Disease Prevention Section of the Division of Public Health (DPH), Department of Health and Social Services (DHSS).

Under the State of Delaware's 4203 DCTP regulation, "uninsured" is defined as a person who meets all technical, financial, and residency requirements of this regulation, in accordance with 8 DE Reg. 1144 (02/01/05) and 18 DE Reg. 67 (07/01/14).

Eligibility includes but is not limited to the following:

- The applicant must need treatment for cancer in the opinion of the applicant's licensed physician of record. Cancer treatment will not include routine monitoring for pre-cancerous conditions, or monitoring for recurrence during or after remission.
- The applicant must be a Delaware resident at the time of cancer diagnosis. A Delaware resident is: an individual who lives in Delaware with the intention to remain; or where the individual is living and has entered into a job commitment or is seeking employment, whether or not currently employed.
- The applicant must have countable household income that is less than 650% of the Federal Poverty Level (FPL).
- The DCTP is payer of last resort and will only provide benefits to the extent that they are not covered by other plans.

The 4203 DCTP regulation was amended effective July 1, 2014 to update the technical, financial, and residency eligibility requirements for the DCTP. Amongst the most noticeable changes are:

- The addition of a new disposition of applications. The new disposition of "Temporary Eligibility" has been added. Applicants are provided temporary eligibility if they meet all technical, financial, and residency eligibility requirements except for those defined in Section 4.1.5 of the regulation.
- The addition of Section 10.3 states: when temporary eligibility is terminated or a disposition of ineligibility

is received, applicants may request a financial hardship waiver and submit to DHSS for review to determine if a significant financial hardship exists.

- o *A request for financial hardship cannot be submitted without going through the entire DCTP application process.
- o Financial hardship is defined as follows:
 - Maximum out-of-pocket expenses for cancer treatment defined by patients health insurance is more than 15% of their income (does not include premiums).
- o If approved, DCTP will pay for co-pays and co-insurances for cancer treatment services until the deductible is met.
- o When applying for the financial hardship waiver, patients are to submit the following documents:
 - Income verification: (three consecutive pay stubs; social security income; unemployment compensation; etc.)
 - Insurance verification (document stating maximum out-of-pocket for plan)

Finally, as a result of Medicaid expansion and in collaboration with the DHSS Division of Medicaid and Medical Assistance (DMMA), the DCTP implemented the process of having all applicants complete a Medicaid application when applying for the DCTP. This is to ensure the applicant is enrolled in the correct program with ease and efficiency from the beginning. The DCTP program will evaluate all Medicaid applications prior to sending them to DMMA for processing. This new process will eliminate processing delays if the applicant is determined to be Medicaid eligible.

To apply for the DCTP, patients should call 1-800-996-9969. If providers have any questions regarding the regulations or the DCTP, call DPH's Comprehensive Cancer Control Program at 302-744-1040.

Delaware Regulations: <http://regulations.delaware.gov/AdminCode/title16/Department%20of%20Health%20and%20Social%20Services/Division%20of%20Public%20Health/Health%20Promotion%20and%20Disease%20Prevention/4203.shtml>

JOIN US FOR THE DELAWARE CANCER CONSORTIUM RETREAT

Creating a Culture of Prevention Through Physical Activity

The Role of Physical Activity in Cancer Prevention and Health Promotion in Youth

TUESDAY, APRIL 25, 2017 | 8:30 A.M. TO 3 P.M.

Dover Downs Hotel and Casino
1131 N. DuPont Highway, Dover, DE 19901

FOCUS AREAS

- Review of national standards
- Best practices in physical education and physical activity

ATTENDANCE IS FREE

For more information, call 302-744-1020.



The Delaware Cancer Consortium Retreat: The Role of Sport and Physical Activity in Cancer Prevention

Kate Smith, M.D., M.P.H.

On Tuesday, April 25, 2017, the Delaware Cancer Consortium held a retreat at the Dover Downs Hotel & Casino. This all day event brought attention to physical activity in children and the role it plays in preventing cancer. A wide variety of locally and nationally renowned speakers expressed support to increase the physical activity of both children and adults in an effort to increase the health of Delawareans of all ages.

The day began with Secretary of Health and Social Services Kara Odom Walker, M.D. Dr. Walker reminded the audience that physical activity is known to help many different health conditions, including cardiovascular health and people with chronic diseases, as well as cancer. Professor I-Min Lee, M.D., M.P.H., Sc.D., epidemiologist with the Harvard School of Public Health, taught the audience that health behaviors track over a lifetime: the more active a child is, the more likely they will be active as an adult. She also discussed her research, Association of Leisure-Time Physical Activity with Risk of 26 Types of Cancer in 1.44 Million Adults, published in the Journal of the American Medical Association in 2016. She and her co-authors concluded that the risk of 13 of the 26 cancers could be reduced by increasing a subject's physical activity.

The morning's keynote speaker was Mr. Tom Farrey, Executive Director of the Sports and Society Program with the Aspen Institute. Mr. Farrey tasked the audience with reimagining the concept of "sport" to include all children, no matter their age, gender, or level of ability. This reimagining seeks to increase every 12 year old's ability, confidence, and desire to be physically active. Each of these components will give children the foundation to be active for life, thus decreasing their future risk of cancer.

The Honorable Bethany Hall-Long, Lieutenant Governor of the State of Delaware incited the audience to continue working to prevent cancer in the population of the First State, and reminded everyone that getting children interested in exercise and physical activity is half the battle.

Irene Cucina, D.P.E., past-president of the SHAPE America program discussed how important having physical education and physical activity was to children, and discussed how it was possible to achieve the national standards of 60 minutes of physical activity per day per child in Delaware.

Over lunch, the audience was treated to video testimonials about the importance of cancer screenings.

After lunch, the Honorable John C. Carney, Governor of the State of Delaware tasked the audience with increasing the physical activity of all children in Delaware. He reminded everyone that just because Delaware was small, did not mean that it could not get things accomplished.

Mary Puckett, Ph.D., of the Division of Cancer Prevention and Control of the CDC taught the audience about some of the best practices regarding including physical activity and exercise into a child's school day.

A panel discussion wrapped up the afternoon, with Deborah Bagatta Bowles (YMCA), Madeline Bayard (Rodel Foundation), Deb Buenaga (Preston's March for Energy), and Jennifer Robbins, M.D. (Nemours Al DuPont Hospital) taking questions from the audience about different types of programs and options available for Delaware schools and children.

Finally, Karyl T. Rattay, M.D., M.S., Director of the Division of Public Health, Delaware Health and Social Services gave the audience their call to action: to take everything presented at the retreat and use it in the best of their abilities to increase the physical activity levels of the children and adults, in order to create a healthier, happier Delaware.



Katherine Smith, M.D., M.P.H.

Dr. Smith has a background in medicine and public health, and has led research projects on foreign and domestic immunization practices. The results of her research have led to new practices for heat-stable vaccines and high-heat cold chain breaks in New South Wales, Australia. She is currently the program manager for the Immunization Coalition of Delaware, and works to increase the public's knowledge of vaccines and their role in increasing a community's overall public health

Delaware Cancer Registry Regulations

Delaware Cancer Registry (DCR) regulations that were effective July 1, 2014 require non-hospital providers (physicians and ambulatory surgery centers) to report cancer cases using the Centers for Disease Control and Prevention (CDC) Web Plus electronic reporting software. A minimal amount of demographic, diagnostic, and treatment information is required to be reported. Web Plus is a secure web-based tool that allows facilities to confidentially enter and submit tumor reports to the DCR.

Who Must Report Cancer Cases?

All health care facilities that diagnose or treat cancer are required to report cancer case information diagnosed on or after January 1, 1996. Reporting health care facilities include all hospitals, laboratories, physicians, and free-standing health care facilities. Chapter 32 of the Delaware Cancer Control Act, states: “Those required to report to the Department occurrences of cancer and benign tumors* shall include:

1. Any physician, surgeon, dentist, podiatrist, or other health care practitioners who diagnose or provide treatment for cancer or benign tumors;
2. The designated representative of any hospital, dispensary, asylum, or other similar public or private institution that diagnoses or provides treatment for cancer or benign tumors; and
3. The designated representative of any laboratory that examines tissue specimens which disclose the existence of cancer or benign tumors.

**The only benign tumors currently required to be reported to the Delaware Cancer Registry (DCR) are brain and central nervous system tumors.*

Why Report Cancer Cases?

Reporting of all reportable cases is vital to analyzing Delaware’s cancer incidence and mortality rates. Approximately 15% of Delaware cases of cancer or benign tumors never present to a hospital system for diagnosis or treatment. The most common types of cancer diagnosed or treated outside a hospital setting include: melanoma, non-invasive bladder tumors, small eye tumors, oral or genital tumors, some prostate and breast tumors, tumors in colorectal polyps, lymphoma, leukemia, multiple myeloma, myelodysplastic syndrome, polycythemia vera, and other bone marrow primaries.

Meaningful Use Stage 2 (MU2) – Electronic Health Record Cancer Reporting

- In February 2015, the DCR declared readiness to receive cancer data from eligible professionals (EPs) using certified electronic health record (EHR) technology. EPs seeking to meet Meaningful Use Stage 2 (MU2) public health objectives by reporting cancer data to the DCR must register their intent to do so with the DCR.
- Additional information on disease occurrences reportable to the DCR, reporting instructions for both hospitals and non-hospital reporters, and MU2 registration can be found online at: <http://dhss.delaware.gov/dhss/dph/dcr/home.html>.

[1 Del. Code Title 16, Chapter 32, § 3201-3209](#)

CANCER LEXICON

OF TERMS

A

ABO-incompatible transplants – very young children, with immune systems that have not yet fully developed, can sometimes receive organs from otherwise blood-type incompatible donors.

Acute - A condition that occurs quickly, with severe symptoms.

Acute Lymphocytic Leukemia (ALL) – a type of cancer in which abnormal lymphocytes are produced

Acute Myelogenous leukemia (AML) – a type of cancer in which abnormal granulocytes are produced

Allogenic transplant – a procedure in which cells, tissue, organs are transplanted to a person from a genetically different, compatible donor of the same species. Most human tissue and organ transplants are allografts. Sometimes these transplants are rejected because the recipient's immune system identifies the new organ as foreign, and tries to destroy it.

Alopecia – a skin disease leading to hair loss on scalp (and sometimes body)

Alternative therapy – any practice not part of mainstream medicine used instead of conventional medical techniques; ie: reiki, aromatherapy

Anemia – a decrease in red blood cells, often due to chronic disease or vitamin deficiency.

Anesthesia – use of medicine to prevent the feeling of pain or sensation during surgery and/or other procedures that might otherwise be painful. Can be local (numbing only an area of the body) or general (makes patient fall asleep).

Anesthesiologist – a doctor specializing in giving and managing anesthetics for procedures, also helps with the treatment and management of chronic pain

Angiogram – a procedure that uses injectable dye to see the blood vessels and blood flow of the heart. It can be used to identify certain kinds of tumors.

Antibodies – Proteins that recognize and help to fight off bacteria and viruses. Part of the immune system.

Apheresis – a procedure that removes the blood and separates it into its main parts (plasma, platelets, and white blood cells), so that certain blood parts can be removed. The remaining blood can then be re-transfused into the person

Aplastic Anemia – a condition in which the bone marrow cannot make enough red blood cells. This can be due to viruses, toxins, radiation, medications, etc

Astrocyte – a type of neuron in the brain

Astrocytoma – a tumor of the astrocytes in the brain

Autograft – the transplant of tissue into the same person. This is sometimes done with surplus tissue, tissue that can regenerate (ie: skin graft), or tissues more desperately needed elsewhere (vein extraction for coronary artery bypass). Sometimes the autograft is done to remove the tissue and treat it, before returning the tissue to the patient (ie: stem cell autograft, storing blood before surgery).

B

Benign – a term used to describe tumors that are slow-growing, non-cancerous, and do not spread into the surrounding tissue

Bilateral – found on both sides of the body (ie: in both lungs, in both kidneys)

Biologic Response Modifiers (BRM) – See: Immunotherapy. BRMs are substances that help the immune system fight cancer, decrease side effects from treatments, and fight infections and other diseases. They stimulate the immune system to help it do its job more effectively.

Biologic therapy – See: Immunotherapy

Biopsy – the removal of a sample of tissue from the body for further examination

Blast Cell – an immature blood cell. Blast cells can become red blood cells, white blood cells, or platelets

Blastoma – a tumor caused by blast cells

Bone Marrow – thick, spongy liquid inside the bones. Makes blood cells (white blood cells, red blood cells, and platelets).

Bone marrow transplant – replaces unhealthy bone marrow with new, healthy bone marrow cells from a donor.

Breast cancer – tumor developing in breast cells

C

CAM – acronym standing for Complimentary and Alternative Medicine

Cancer – a group of many related diseases that occur when abnormal cells grow, divide uncontrollably, and spread very quickly. The type of cancer depends on which cells have become abnormal.

Carcinogen – a substance that can cause cancer (ie: tobacco smoke)

Carcinoma – same as the word cancer

CAT Scan – Computerized Axial Tomography Scan, CAT scan. A type of X-ray in which a machine rotates around a patient and creates a picture from different angles. A CAT scan shows muscles, bone, and body structures *Image credit: <https://www.radiologyinfo.org/en/info.cfm?pg=bodyct>*



Central Nervous System – the brain and spinal cord

Cerebrospinal fluid – a clear, colorless liquid around the central nervous system. It delivers nutrients and cushions the brain and spinal cord.

Chemotherapy – the use of chemical compounds (drugs, medicine) to treat cancer. Often several medicines are used together to attack the cancer cells in different ways.

Chronic – an illness that lasts for a long time, or goes away and comes back. (ie: Diabetes)

Chronic Myelogenous Leukemia (CML) – a relatively rare leukemia. White blood cells reproduce until there are too many of them for the body to handle.

Clinical Trial – a study that evaluates new drugs or procedures for safety and effectiveness. A trial usually lasts 2-4 years before a drug or procedure is determined safe for humans.

Phase	Testing for	General Sample Size	Outcomes
I	Safety	20-100 Healthy Volunteers	Are there any common side effects?
II	Effectiveness in a specific population	100-500 Patients	Does it actually work as intended? How well does it work?
III	Confirmation	1,000+ people	Compares a new treatment or procedure to the standard
IV	Long Term Safety in a diverse population	Real Life Patients	Are there any side effects in previously un-tested population groups, or long-term side effects? (similar to a Registry)

Colony Stimulating Factors – substances that stimulate the production of blood cells (white blood cells, red blood cells, and platelets) in the bone marrow, and promote their ability to function. These factors support the immune system.

Complementary Therapy – the use of alternative treatments in addition to (not instead of) conventional medical therapies.

Complete Blood Count (CBC) – a common blood test that evaluates the number of red blood cells, white blood cells, and platelets in a person’s blood

Computed Tomography Scan – Procedure. see CAT scan

Cord blood – blood taken from the umbilical cord after a baby is born. This blood can be collected and stored to supply the same kinds of stem cells as a bone marrow donor.

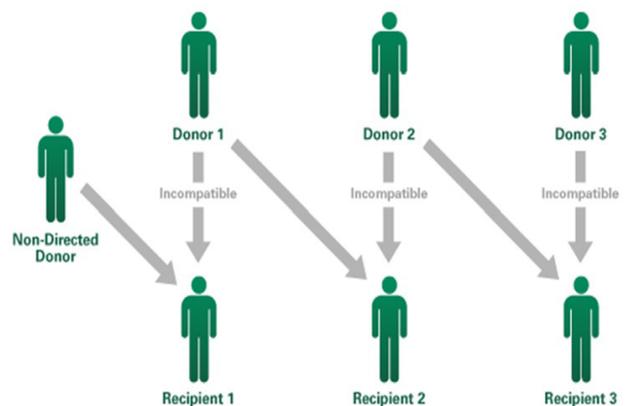
Core biopsy – a procedure in which a hollow needle is inserted into a lymph node or tissue to remove a small amount of tissue for examination

CT Scan – see CAT Scan

Cyberknife – a type of radiosurgery. The CyberKnife System is a unique, robotic system designed to deliver high-precision radiation

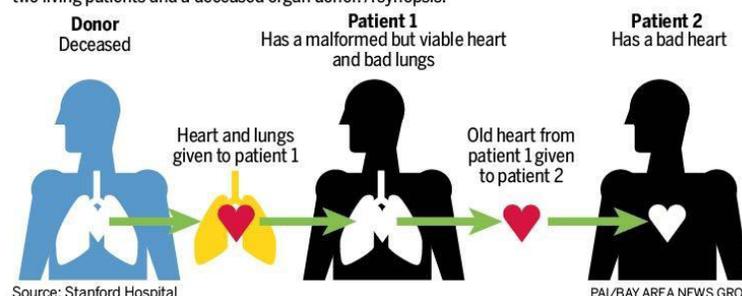
D

Domino Transplants – a multiple donation chain. In general, a living donor will donate to the highest recipient on the waiting list, and the transplant center uses that donation to facilitate multiple transplants that are otherwise impossible due to antibody or blood type barriers. (Image credit: <http://trialx.com/curetalk/2012/02/28/domino-chain-of-kidney-transplants-and-live-kidney-donations/>). Domino transplantation can also be done when a patient needs to have both lungs replaced. It is technically easier to replace both the heart and lungs, so the patient will receive both from a deceased donor. Then, their heart will be given to another person who only needs a new heart (image credit: <http://www.mercurynews.com/2016/03/17/rare-transplant-procedure-at-standford-hospital-saves-two-womens-lives/>). This is used in patients with cystic fibrosis.



THE DOMINO EFFECT

Stanford Hospital performed a rare “domino” transplant – a complicated procedure involving two living patients and a deceased organ donor. A synopsis:



Drug Resistance – when cancer does not respond to a medicine or treatment

Dysplasia – abnormal changes in the structure or organization of a group of cells

Dyspnea – difficulty breathing, shortness of breath

E

Edema – swelling caused by fluid buildup in the tissues. Commonly seen in the feet, legs, and around the eyes.

Eosinophil – a type of white blood cell that fights allergic reactions.

Ependymoma – a tumor in the lining of the brain ventricles.

Ewing Sarcoma – bone cancer, usually located in the leg or pelvis

Excisional biopsy – surgery to remove an entire lump, tumor, or suspicious area for diagnostic purposes

External Radiation – Radiation therapy that involves visiting the hospital or treatment center as an outpatient. 4-5 days a week for several weeks or shorter.

F

G

Gallium Scan – an injection of Gallium is given to a patient to detect tumors, and inflammation

Gene therapy – a procedure that uses altered and engineered genes to correct specific disorders or genetic defects.

Genetics – aka Heredity. The study of genes, physical traits and characteristics of a person, and how those traits get passed from one generation to the next.

Genetic Counseling – uses family history, medical records, and genetics to evaluate and determine potential risk factors and disorders that might be inherited. May also provide clues to how a disorder or disease may be prevented.

Genetic Testing – Analyzing small samples of blood, saliva or tissue to determine whether a patient carries a certain gene(s) for inherited disorders.

Germ Cells – reproductive cells that develop into sperm and eggs.

Germ Cell Tumors – tumors that begin in the germ cells.

Grade – Describes the aggressiveness of a certain cancer. The lower the grade, the less aggressive the cancer, and the greater the chance for a cure.

Granulocyte – White blood cell. Types of granulocytes include basophils, eosinophils, and neutrophils. Contains grain-like particles of enzymes that let it fight bacteria and infections.

Growth Factor – a substance that effects how cells grow and divide. Are generally proteins produced in the body, but may be produced in a lab and used as part of immunotherapy.

H

Hematologist – a doctor specializing in blood disorders

Hematology – the study of blood and blood forming tissues

Hematopoietic cell – a stem cell that gives rise to all the other blood cells (white blood cells, red blood cells, platelets)

Hemoglobin – a substance in red blood cells that carries oxygen through the blood to different parts of the body

Hepatoblastoma – a type of liver cancer

Hodgkin Disease – a type of lymphoma that usually starts in the B lymphocytes

Hospice – a type of palliative care for people in the last stage of their illness.

I

Imaging Studies – safe and painless tests using magnetic fields (MRI, CAT Scan), radio waves (ultrasound), and X-Rays to produce detailed pictures of the body's organs and structures

Immune System – helps protect the body from disease by destroying bacteria, viruses, and other infectious agents. Includes white blood cells and lymph nodes. *Image Credit: <https://medlineplus.gov/immunesystem.html>*

Immunosuppression – when the body's immune system has lost effectiveness. This can be due to certain drugs (chemotherapy), procedures (radiation therapy), or diseases (HIV/AIDS)

Immunotherapy – a type of treatment that mobilizes the body's immune system to fight cancer.

Implant – anything foreign placed in the body. In radiation therapy, an implant is radioactive material that is placed within or near cancer cells or a tumor to deliver radiation therapy directly.

Incisional Biopsy – A surgical procedure in which a sample of suspicious tissue is removed for testing and diagnosis

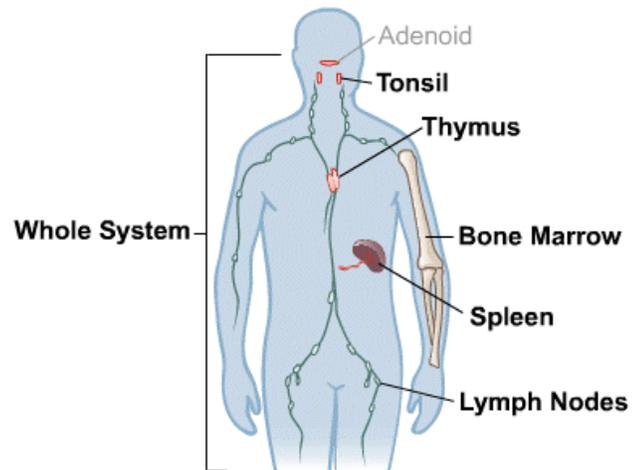
Internal Radiation Therapy – Radioactive material may be placed in small tubes that are implanted into the tumor or body cavity, or be swallowed, or be injected into the bloodstream. This generally requires inpatient care for several days of careful monitoring.

Isograft – a subset of allografts and allographic transplantation. Organs or tissues are transplanted from a donor to a genetically identical recipient (ie: a twin). Although they are anatomically identical to an allograft, an isograft will not trigger an immune response in the recipient.

J

Juvenile Myelomonocytic Leukemia (JMML) – A rare type of cancer in which too many immature blood cells are made in the bone marrow. Occurs in children younger than 2 years.

K



L

Leukemia – cancer of the white blood cells (leukocytes).

Leukocyte – white blood cell. Includes: neutrophils, eosinophils, basophils, monocytes, lymphocytes.

Limb-Salvage Surgery – a surgical procedure done to remove a bone (or part of a bone) containing cancer, but the limb is saved from amputation.

Locally Invasive – a tumor spreading to the tissues surrounding it.

Lumbar Puncture – aka: Spinal Tap. A procedure in which a small amount of the cerebrospinal fluid is removed from the mid-back and examined for diagnostic purposes.

Lumpectomy – a procedure in which part of the breast containing a tumor is removed.

Lymph – Clear, watery fluid containing protein, salts, glucose, urea, white blood cells, and other substances. Lymph flows throughout the body in its own vessels. Part of the immune system.

Lymph Node – Part of the lymph system, nodes filter lymph to remove foreign bodies (bacteria that have been identified by white blood cells). They have a high concentration of white blood cells, and become swollen when a person has an infection.

Lymph Vessels – Vein-like structures that carry lymph throughout the body.

Lymphangiogram (LAG) – a test that uses injectable dye and x-rays to examine the lymph system.

Lymphatic System – network of tissues and organs that carry lymph throughout the body. Includes lymph nodes, thymus, spleen, adenoids, tonsils, and bone marrow. *Image credit: <http://www.merckmanuals.com/home/heart-and-blood-vessel-disorders/lymphatic-disorders/overview-of-the-lymphatic-system>*

Lymphocyte – a white blood cell found in lymph nodes that makes antibodies.

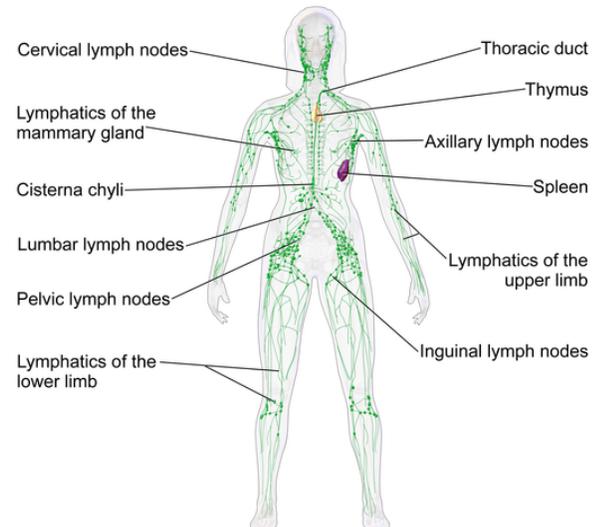
Lymphocytic Leukemia – cancer of the lymphocytes.

Lymphoma – cancer that starts in the lymphatic system.

M

Magnetic Resonance Imaging (MRI) – a diagnostic imaging test that uses a magnetic field and radio waves to produce detailed pictures of the body's organs and structures. *Image credit: <http://www.radiologyinfo.org/en/info.cfm?pg=bodymr>*

Mammogram – a very specific x-ray taken of the breast to screen for breast cancer in women with no symptoms of the disease (screening mammogram), or to check for breast cancer after symptoms appear (diagnostic mammogram). *<https://www.cancer.gov/types/breast/mammograms-fact-sheet>*



Mastectomy – surgically removing the whole breast. Medical History – information about a person’s health, their family’s health, and other issues that may have bearing on their diagnosis or treatment.

Melanocytes – skin cells. They produce the pigment that gives skin its color (the more melanocytes a person has, the darker their skin color).

Melanoma – Cancer of the melanocytes.

Metastasis – the spread of cancer from the original site to other parts of the body.

Mutation – any change in a gene.

Myelogram – a diagnostic imaging procedure that uses contrast dye, x-ray or a CT scan to look for problems in the spinal canal, including the spinal cord, nerve roots, and other tissues. *Image credit: http://www.hopkinsmedicine.org/healthlibrary/test_procedures/neurological/myelogram_92,P07670/*

N

Nephrologist – a doctor specializing in the kidneys

Neuroblast – a primitive nerve cell that will develop into a neuron and other nerve tissue

Neuroblastoma – cancer of the neuroblasts.

Neurosurgeon – a surgeon specializing in the brain and nervous system

Neutropenia – a type of anemia in which the body has low levels of neutrophils

Neutrophil – the white blood cell responsible for fighting illness and infection

Non-Hodgkin Lymphoma – cancer in the lymphatic system, includes all types of lymphoma except Hodgkin’s lymphomas.

O

Oncogenes – genes causing cancer cells to grow and duplicate that, under certain circumstances, can lead to cancer

Oncologist – a doctor specializing in cancer

Oncology – the study of cancer, including its diagnosis and treatment

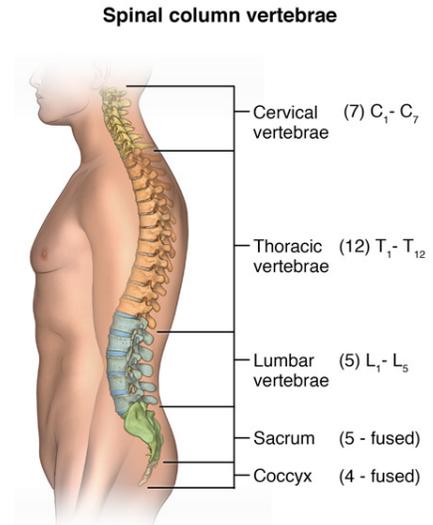
Ophthalmologist – a doctor specializing in the medical and surgical procedures and treatments of the eye

Osteosarcoma – the most common type of bone cancer

Optometrist – a doctor specializing in the eyes who is not certified to do surgery.

P

Pathologist – a doctor specializing in diagnosing and classifying diseases. They often study cell and tissue samples that have been biopsied to identify diseases and conditions.



Pediatric Oncologist – a doctor specializing in the treatment of cancer in children, and specializing in those cancers that generally affect children over adults

Pediatrician – a doctor specializing in the physical, emotional, and social health of children from birth through adolescence.

Physical Therapist – a specialist who uses exercises, stretches, and other techniques to help patients improve mobility, decrease pain, and reduce disability related to illness or injury

Plasma – the part of the blood left over when all the red blood cells, white blood cells, and platelets are removed. Plasma is a yellowish liquid that carries nutrients, hormones, and proteins throughout the body.

Platelets – blood cells that cause clotting (which stops bleeding)

Port – a medical implant inserted under the skin and attached to a vein that allows medications, blood, and nutrients to be given intravenously. Implanting a port eliminates the need for repeated needle sticks to start an IV line or draw blood in patients who require these procedures frequently (ie: patients receiving chemotherapy).

Primary site – the organ or area where cancer begins. The type of cancer is always identified by its primary site.

Prognosis – an estimate, given by a health care provider, of how well a treatment is working, and how likely (or unlikely) the disease is to be cured

Prosthesis – an artificial limb

Protein – molecules that help the body function properly. Protein from food is used by cells to make specialized protein molecules that maintain muscles, make hemoglobin, maintain blood, etc.

Protocol – a standard method or plan. Protocol for certain cancer may be specific chemotherapies, blood transfusions, procedures and tests.

Q

R

Radiation Oncologist – a doctor specializing in using radiation to destroy cancer cells

Radiation Therapist – an operator who is specially trained on the equipment used to deliver radiation therapy

Radiation Therapy – aka radiotherapy, irradiation, x-ray therapy. One of the most common forms of cancer treatment. High energy radiation from x-rays, gamma rays, or other sources is used to kill cancer cells and shrink tumors. This prevents cells from growing or reproducing by destroying them.

Radiologist – a doctor specializing in reading and interpreting x-rays and scans

Radical surgery – a form of radiation therapy that uses precisely targeted radiation to destroy tumors. There is no actual cutting required, the “surgery” refers to the high level of precision in the energy beams. Commonly used for treatments of the brain and spine.

Red blood cells – part of the blood that delivers oxygen to all parts of the body. Aka erythrocytes.

Reed-Sternberg Cells – large, unusual cells that are a sign of Hodgkin disease.

Regimen – treatment plan/system. This can include things like diet, exercise, treatments, etc.

Relapse – the reappearance of cancer after it has been treated

Remission – when cancer signs and symptoms disappear or are significantly reduced

Retinoblastoma – malignant tumor of the eye, generally appears in the first three years of life

Rhabdomyosarcoma – cancer in the soft tissue of the skeletal muscles that is more frequently found in the muscles of the trunk and extremities (arms and legs)

Risk Factor – anything increasing a person’s chance of getting cancer (ie: smoking, asbestos exposure, genetics, family history)

S

Sarcoma – a type of cancer that begins in the connective tissue (bone, cartilage, fat, muscle, blood vessels, etc)

Secondary tumor – tumors of cells that have metastasized from the primary site to somewhere else in the body

Side effects – unwanted reactions to medication or therapy. Common chemotherapy side effects include hair loss and fatigue.

Spinal Tap – see: lumbar puncture

Stem cells – primitive cells found in the bone marrow, capable of developing into the three different types of mature blood cells (red blood cells, white blood cells, and platelets)

Stem Cell Transplant – a procedure that introduces stem cells from a donor into a patient’s body in the hopes that the new cells will rebuild the patient’s immune system

Stereotactic Body Radiation Therapy (SBRT) – a form of radiosurgery that uses targeted radiation to destroy tumors located outside of the brain and spine

T

Testicular Cancer – Cancer originating in the testicles. The most common cancer in males 15-35 years

Transplant – a medical procedure in which something (usually an organ) is removed from one body and placed in the body of a recipient, to replace something damaged or missing. There are several types of transplant: autografts, allografts, isografts, and xenografts. Transplants may be completed in a one-to-one fashion, or may be in chains, as is the case in domino transplantation.

Tumor – abnormal cells grouped together in a mass or lump. Can be malignant or benign.

U

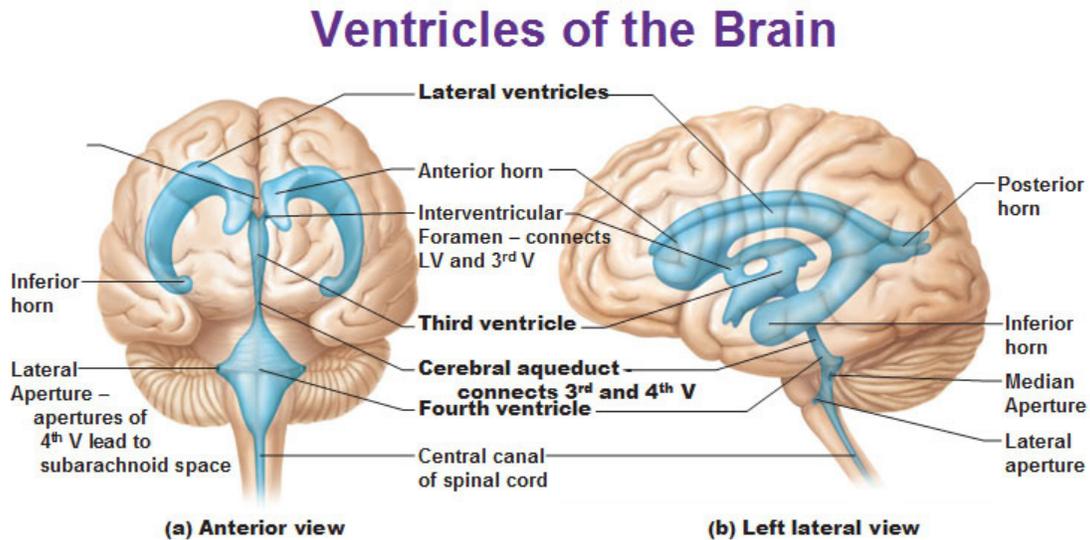
Ultrasound – aka sonography. A procedure in which sound waves are bounced off areas of the body to produce a picture of the internal organs for doctors to examine. Often used to examine abdominal structures.

Unilateral – found on one side of the body (ie: the spleen is a unilateral organ)

Urologist – a doctor specializing in diseases, disorders, and conditions of the urinary tract (bladder, ureters, prostate, etc)

V

Ventricles – cavities within the brain producing cerebrospinal fluid. There are two lateral ventricles (with anterior, posterior, and inferior horns). These ventricles connect to the third ventricle by the interventricular foramen. The third ventricle is connected to the fourth ventricle by the cerebral aqueduct. *Image credit: <http://antranik.org/central-nervous-system-intro-to-brain-and-ventricles-medulla-oblongata-pons-mid-brain-and-cerebellum/>*



W

White blood cell – aka leukocyte. Part of the immune system, a WBC attacks invaders like viruses and bacteria. Each type of WBC (neutrophil, eosinophil, basophil, monocyte, and lymphocyte) has a different role in the immune system.

Wilms tumor – a cancer originating in the kidneys, usually seen in children

X

X-Ray – using radiation to take pictures of the skeletal system

Xenograft/Xenotransplantation – a transplant of organs or tissues from one species to another. For example, a porcine heart valve transplant (pig to human), piscine-primate transplant of islet (fish to non-human primate transplant of pancreatic tissue). This type of transplant is extremely dangerous due to the increased risk of non-compatibility, rejection, and disease carried in the tissue.

Y

Z



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Questions? Contact us at Sarahfaye.F.Dolman@ChristianaCare.org or 302-733-5868.

Work supported by an Institutional Development Award (IDeA) from the National Institute of General Medical Sciences of the National Institutes of Health under grant number U54-GM104941 (PI: Binder-Macleod).

Cancer

A term for diseases in which abnormal cells divide without control. The cells can invade nearby tissues, and spread to other parts of the body through blood and lymph systems. AKA: malignancy.

Name	Cancer Began In the	Other Factors
A		
Acute Lymphoblastic Leukemia (ALL)	White blood cells, Bone Marrow	Generally seen in children
Acute Myeloid Leukemia (AML)	Granulocytes (WBC), Bone Marrow	Generally seen in older adults
Adenoma	Glands	Benign Tumor
Adenocarcinoma	Glands	Malignant Tumor
Adrenocortical Carcinoma	Adrenal Glands	
Anal Cancer	Anus	Risk Factor: HPV infection
Appendix Cancer	Appendix	
Astrocytoma	Brain (astrocytes)	Most common glioma
B		
Basal Cell Carcinoma	Skin	Most common skin cancer
Bladder Cancer	Bladder	
Breast Cancer	Breast	Generally seen in females, but can occur in males
Burkitt Lymphoma	Lymphatic System (B Lymphocytes)	Risk Factor: immunosuppression (ie: HIV/AIDS)
C		
Carcinoid Tumor	Endocrine System & GI Tract	
Cervical Cancer	Cervix	Risk Factor: HPV infection
Chondrosarcoma	Cartilage	30% of skeletal system cancers
Cholangiocarcinoma	Bile Duct	
Chordoma		Generally seen in children
Chronic Lymphocytic Leukemia (CLL)	White blood cells (B Cells)	Most common type of leukemia in adults
Chronic Myelogenous Leukemia (CML)	White blood cells (myeloid)	Generally seen in adults
Colorectal Cancer	Colon/Rectum	Generally seen in adults
Craniopharyngioma	Brain	Generally seen in children
Cutaneous T-Cell Lymphoma	Lymph	Risk Factor: Immunosuppression (ie: HIV/AIDS)
D		
Desmoplastic Small-Round-Cell Tumor	Abdomen	Generally seen in male children
Ductal Carcinoma In Situ (DCIS)	Breast	Generally seen in females

E

Embryonal Tumors	Brain/CNS	Generally seen in children
Endometrial Cancer	Uterus	May be hereditary
Ependymoma	Brain	
Esophageal Cancer	Esophagus	Risk Factor: Barrett's Esophagus; alcohol
Esthesioneuroblastoma	Brain	Affects mostly children
Ewing's Sarcoma	Bone	Generally seen in teens & young adults

G

Gallbladder Cancer	Gallbladder	Uncommon
Gastric Cancer	Stomach	Risk Factor: H. pylori infection
Gastrointestinal Stromal Tumors (GIST)	Stomach	
Germ Cell Tumors	Sperm/Eggs	
Gestational Trophoblastic Disease	Placenta	Generally seen in pregnant females
Glioma	Brain/Spine (glial cells)	80% of all malignant brain tumors

H

Hairy Cell Leukemia	Blood	Sub-type of CLL
Hepatocellular Cancer	Liver	Risk Factor: Hepatitis B or C infection
Hodgkin Lymphoma	White Blood Cells	Risk Factor: Epstein-Barr Virus
Hypopharyngeal Cancer	Back of throat	Risk factor –alcohol, tobacco

I

Intraocular Melanoma	Eye	Risk Factor: UV Light
Islet Cell Tumors	Pancreas	

K

Kaposi Sarcoma	Soft Tissue	Risk Factor: Major Immunosuppression (ie: full blown AIDS)
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L

Laryngeal Cancer	Larynx/Voice Box	Risk Factor: Tobacco; alcohol
Leukemia	White Blood Cells	Most common cause of cancer in children
Liposarcoma	Fat cells	Rare
Lymphoma	White Blood Cells (Lymphocytes)	Includes Hodgkins's or Non-Hodgkin Lymphoma; Multiple Myeloma

M

Malignant Fibrous Histiocytoma	Soft Tissue	Diagnosis of Exclusion
Medulloblastoma	Brain	Most common type of pediatric malignant brain tumor
Melanoma	Skin (melanocytes)	Malignant, Risk Factor: UV Light
Merkel Cell Carcinoma	Skin	Risk Factor: Merkel Cell Polyomavirus (MCV)
Mesothelioma	Mesothelium (tissue layer covering internal organs)	Most commonly affected area: lungs. Over 80% due to asbestos exposure
Microglioma	Brain/CNS	Risk Factor: Immunodeficiency
Multiple Myeloma	White Blood Cells (Plasma Cells)	Risk Factor: Alcohol, obesity
Myelodysplastic Syndromes	Bone Marrow	Risk Factor: Chemotherapy or radiation therapy

N

Nasopharyngeal Cancer	Nose & Throat	
Neuroblastoma	Nervous Tissue	May be hereditary
Non-Hodgkin Lymphoma	Blood	Generally seen in older adults (65-75)
Non-Small Cell Lung Cancer	Lung	Risk Factor: Tobacco Smoking

O

Oligodendroglioma	Brain	Generally seen in adults
Oral Cancer	Mouth	Risk factor –alcohol;tobacco
Oropharyngeal Cancer	Mouth & Throat	Risk factor –alcohol;tobacco
Osteosarcoma	Bone	Generally seen in teenagers & young adults
Ovarian Cancer	Ovaries	May be hereditary

P

Pancreatic Cancer	Pancreas	Rare before age 40
Parathyroid Carcinoma	Parathyroid Gland	Rare
Penile Cancer	Penis	Risk Factor: HPV
Pharyngeal Cancer	Neck	Risk Factor: HPV
Pheochromocytoma	Adrenal Glands	May be hereditary
Pituitary Adenoma	Pituitary Gland	
Pleomorphic Undifferentiated Sarcoma (PUS)	Soft Tissue	
Pleuropulmonary Blastoma	Lung	Generally seen in children
Primary Brain Lymphoma	Brain	Risk Factor: Immunodeficiency

Prostate Cancer	Prostate Gland	Generally seen in older males
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R

Rectal Cancer	Rectum	Generally seen in older adults
Renal Cell Cancer	Kidney	Most common type of kidney cancer in adults
Retinoblastoma	Eye	Most common malignant cancer of the eye in children, may be hereditary, Generally seen in the very young
Rhabdomyosarcoma	Skeletal Muscle	Generally seen in children

S

Salivary Gland Cancer	Salivary Glands	
Small Cell Lung Cancer	Lungs	
Small Intestine Cancer	Gastrointestinal (GI) Tract	
Squamous Cell Carcinoma	Skin	Risk factor – UV light

T

T-Cell Lymphoma	Blood (T-Cells)	
Testicular Cancer	Testes	Young Adults
Thymoma	Thymus gland	Risk Factor: Myasthenia Gravis
Thymic Carcinoma	Thymus gland	
Thyroid Cancer	Thyroid gland	
Transitional Cell Carcinoma	Urinary Bladder	Most common bladder cancer

U

Urethral Cancer	Urethra	Rare
Uterine Cancer	Uterus	Risk Factor: Obesity, Age, HPV infection
Uterine Sarcoma	Uterus	
Urothelial Cell Carcinoma	Urinary Bladder	AKA Transitional Cell Carcinoma

V

Vaginal Cancer	Vagina	Rare
Vascular Tumors	Arteries & Veins	
Vulvar Cancer	Vulva	

W

Wilms Tumor	Kidney	Generally seen in children
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Delaware Resources

American Cancer Society – Delaware – 302-324-4227

92 Reads Way #205 | New Castle, DE

Cancer Care Connection – 302-266-8050 / <http://cancercareconnection.org/>

Cancer Care Connection's mission is to coach people affected by cancer to obtain and use information and referrals to make informed decisions and to take action on their own behalf.

Cancer Care Coordinators

Nursing professionals on staff in every hospital to help coordinate appointments, provide emotional support for you and your family, and arrange transportation. Free to all Delaware residents.

A.I. DuPont Hospital	302-289-0517
Bayhealth Medical Center	302-321-6302
Beebe Healthcare	302-387-4178
Christiana Care Health Services	302-407-0731
Nanticoke Health Services	302-526-1332 ext 2557
St. Francis Hospital	302-715-0876
Veterans Affairs Medical Center	302-725-4434 ext 4702

Cancer Support Community, Delaware - <https://www.cancersupportdelaware.org/>

A statewide non-profit organization whose mission is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. Members are adults, teens, and children with cancer and their family members/care givers. All services provided free of charge.

Candlelighters – 302-657-4553

Offers support for parents of children who have cancer. Group meets every fourth Wednesday, 7 to 9 pm at Alfred I. DuPont Hospital for Children.

Delaware 2-1-1

Cancer Care Helpline – providing patients with access to local and national cancer and human service organizations.

Delaware Breast Cancer Coalition – 302-778-1102 | <http://www.debreastcancer.org/>

Empower the community by raising awareness of breast health issues through outreach, education and support services, in order to facilitate the early detection and treatment of breast cancer.

Delaware Cancer Consortium - <https://www.healthydelaware.org/Consortium>

Mission: to impact the state of health of Delawareans by lowering cancer incidence and mortality rates in Delaware to one of the lowest in the nation, to eliminate all race/ethnicity and economic disparities in cancer, to ensure people in Delaware diagnosed with cancer get the best possible care in an efficient, person-centric way.

Delaware Cancer Treatment Program – 800-996-9969

If you've been diagnosed with cancer and don't have insurance, the DCTP may be able to help pay for your treatment for up to 2 years. Available to Delaware residents who

- Were residents of Delaware when diagnosed with cancer
- Were diagnosed with cancer on or after July 1, 2004
- Have no comprehensive health insurance
- Do not receive benefits through the Medicaid breast and cervical cancer treatment programs
- Meet income guidelines (up to 650% of the Federal Poverty Level)

Delaware Hospice – 800-838-9800 | <https://www.delawarehospice.org/>

Support for individuals living with a serious illness, caring for someone who is ill, or grieving the loss of a loved one.

Delaware Ovarian Cancer Foundation - <http://deovariancancer.org/home>

A non-profit organization to increase ovarian cancer awareness and education in Delaware, support women affected by ovarian cancer, and promote research in the fight of this deadly disease.

First State Prostate Support Group – 302-324-4227 | 800-304-0779

For patients and family members of current or post-treatment prostate-cancer patients. Meetings are the first Wednesday of each month, 6:30 to 7:30 pm at 92 Reads Way, Suite 205, New Castle.

Helen F. Graham Cancer Center & Research Institute

4701 Ogletown-Stanton Road | Newark, DE | 302-623-4500

<https://christianacare.org/services/cancer/>

The Graham Cancer Center features unique multidisciplinary care that includes a team of specialists whom you can see all in one visit, including a surgeon, a medical oncologist or hematologist and a radiation oncologist who will work together to provide you with the best treatment.

The cancer clinical trials program is one of a select group of research centers in the country that participate in the National Cancer Institute's NCI Community Oncology Research Program (NCORP).

The Graham Cancer Center is home to some of the most advanced cancer-fighting technology in the world, including the Cyberknife and da Vinci robotic surgery systems. The Breast Center features Delaware's only dedicated breast MRI scanner.

National Ovarian Cancer Coalition – 302-998-6889 | <http://www.ovarian.org/>

Delaware Valley Chapter. Raises awareness about ovarian cancer and promotes education about the disease.

Nurse Navigators

Nurse navigators can help you prepare for and schedule any cancer screenings you may need. They are also available to discuss expectations and getting your results.

Bayhealth Medical Center	302-566-1202
Beebe Healthcare	302-297-8342
Christiana Care Health Services	302-261-8719
Nanticoke Health Services	302-604-5243 ext 3765
St. Francis Hospital	302-504-6732

Ronald McDonald House of Delaware – 302-656-HUGS | <https://rmhde.org/>

The Ronald McDonald House of Delaware provides a safe, affordable “home away from home” to families of seriously or chronically ill or injured children who are being treated at area hospitals and operates 3 Ronald McDonald Family Rooms within pediatric units of hospitals across Delaware.

Screenings

Screenings allow your healthcare provider to find cancer before it becomes a major health problem. Many types of cancer do not have symptoms, so it is important to have screenings regularly.

Type	Age	Screening/Vaccine	How Often
Breast	Women 18-39	Clinical Breast Exam (CBE)	Annually
	Women 40+	Mammogram & CBE	Annually
Cervical	Women 21-40	Pap Test & Pelvic Exam	Every 5 years with co-testing OR every 3 years
Colorectal	Men & Women 50+	Colonoscopy	Every 10 Years
Lung	Men & Women 55-80 who: <ul style="list-style-type: none"> Smoke or have smoked a pack a day for 30+ years Smoked or have smoked 2 packs a day for 15+ years Currently smoke Quit smoking within the past 15 years 	Low-dose CT scan	Talk to your doctor
Prostate	Average Risk: Men 50+ High Risk: African American Men 40+	Prostate-Specific Antigen (PSA) test with or without a Digital Rectal Exam (DRE)	Talk to your healthcare provider

* These are recommendations based on Screening for Life guidelines, October 25, 2016. Please talk with your doctor or healthcare professional about individual screening recommendations

Screening for Life – 302-744-1040

If you don't have insurance, or if your insurance doesn't pay for cancer screenings, Screening for Life can provide you with the screenings you need when you need them. You are eligible if you:

- Are a Delaware resident
- Have health insurance that doesn't cover screenings
- Are age 18 – 64 and not eligible for Medicaid

- Are 65+ and do not qualify for Medicare
- Meet income guidelines
- Are not eligible for health insurance

Sisters on a Mission – 302-475-0687

Support group for African American women with breast cancer. Meetings are every fourth Monday, 6:30 to 8:30 pm at Westminster Presbyterian Church, Wilmington, DE.

Supporting Kidds – 302-235-5544 | www.supportingkidds.org

Providing a compassionate pathway to healing for grieving children and their families, and to empower the community to support them in the grieving process.

Wellness Community of Delaware – <http://wellnessdelaware.org/>

Dedicated to helping people with cancer and their loved ones by providing free, professionally led programs of emotional support, education, and hope, as an integral part of conventional medical treatment.

Wilmington Delaware Ostomy Association Support Group – 302-463-1687

Support group for those with an ostomy, current or post-treatment for cancer or other conditions. Group meets at the Helen F. Graham Cancer Center & Research Institute.

Women’s Mobile Health Screening Unit – 1-888-672-9647

Screening Van brings breast and cervical cancer screenings to women 40 years and older. The van also offers blood pressure monitoring, tobacco cessation tools, diabetes information, and healthy lifestyle tips.

Young Survivors in Action – 302-778-1102

Offering support for women under 40 who have been diagnosed with breast cancer.

Regional Resources

Abramson Cancer Center of the University of Pennsylvania –| <https://www.pennmedicine.org/cancer>

Hospital of the University of Pennsylvania
3400 Spruce Street | Philadelphia, PA 19104
1-800-978-PENN | 215-662-4000

Fox Chase Cancer Center –| <http://www.fccc.edu>

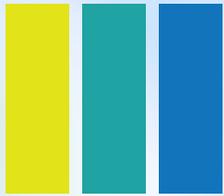
Main Campus:
333 Cottman Avenue | Philadelphia, PA 19111-2497
1-888-369-2427

Kimmel Cancer Center at Thomas Jefferson University – <http://www.kimmelcancercenter.org>

233 S. 10th Street | Philadelphia, PA 19107
215-503-5692

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www.delawaremost.org

To schedule a live training opportunity, contact Kate Smith:

302-733-5571 | ksmith@delamed.org

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From the history and archives collection

This article about Robert H. Frelick, MD is from the Wilmington Morning News on Saturday, October 14, 1950. The headline banner on this date was "Yanks within 65 Miles of Red Capital." President Truman had just announced Wake Island as the location for the final parley with General MacArthur to discuss the final phase of the Korean campaign. Dr. Frelick's medical career spanned decades, and his dedication to cancer diagnosis and treatment was honored with the Lewis B. Flinn President's Award, presented by the Delaware Academy of Medicine in 2009. Dr. Frelick remained engaged in medicine, attending medical grand rounds and other education event until a year before his passing in 2016.

Dr. R. H. Frelick Appointed To Head Carpenter Clinic

He Succeeds Dr. J. F. Hynes in Directing Center for Cancer Diagnosis; Dr. Eduardo Carceres Named as Consultant

Dr. Robert H. Frelick has been appointed executive officer of the Carpenter Tumor Clinic at The Memorial Hospital, it was announced yesterday by Mrs. Grace Little, superintendent of the hospital.

He succeeds Dr. John F. Hynes, director of the clinic for many years, who is devoting full time to private practice.

Under the new arrangements for operation of the clinic, a radiologist on the staff of the Memorial Hospital of New York City has been appointed as consultant. He will come here one day each week for radiation therapy.

The radiologist is Dr. Eduardo Carceres, "who has had many years of intensive training in the field of cancer and is considered an authority on malignant diseases," Mrs. Little announced.

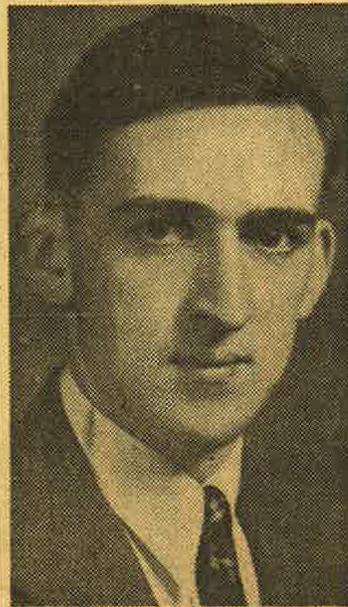
The Carpenter Clinic, established in 1935, has been one of the state's principal centers for diagnosis and treatment of cancer. It was a gift of the late R. R. M. Carpenter, former chairman of the board of directors of the hospital. Mr. Carpenter made the contribution in memory of his parents, Walter S. and Belle M. Carpenter.

Dr. Hynes formerly devoted part of his time to private practice while directing the operation of the clinic. He is now devoting full time to his own practice, with his office at 1100 Jackson Street.

Dr. Frelick had previous experience at the local hospital, having served as medical resident following his release from the Army.

He was born in Potsdam, N. Y., in

Cancer Specialist



Dr. Robert H. Frelick

Dr. Frelick—

Continued From First Page

1920. He was raised in Schenectady and attended Union College, from which he was graduated in 1941 with an A.B. degree. He was graduated from Yale medical school in September, 1944 and interned at New Haven Hospital in surgery.

Dr. Frelick entered the Army in July, 1945 and served for two years, most of the time in Munich, Germany. After leaving the Army, he came to the Memorial Hospital here.

This was followed by a year in the Medical Residency at Memorial Cancer Center, New York City. He completed this work in June, 1950.

Dr. Frelick returned to Wilmington following this and started a practice in international medicine while assuming the directorship of the Carter Clinic on a part-time basis.