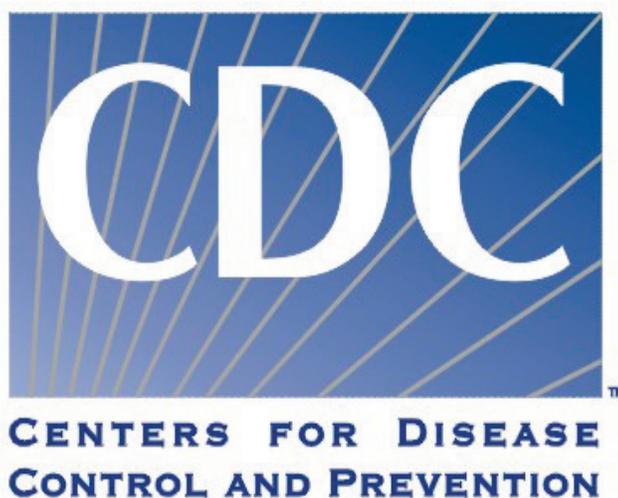


**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
CENTERS FOR DISEASE CONTROL AND PREVENTION  
National Center for Chronic Disease Prevention and  
Health Promotion  
Division of Cancer Prevention and Control**



**Breast and Cervical Cancer Early Detection and Control  
Advisory Committee Meeting  
June 16-17, 2011  
Atlanta, Georgia**

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**Record of the Proceedings**

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## ATTACHMENT 1

### List of Participants

#### **BCCAC Members**

Dr. Amelie Ramirez, Chair  
Dr. George Birdsong  
Dr. Vivien Hanson  
Ms. Gale Johnson  
Dr. Hannah Linden  
Dr. Evan Myers  
Ms. Chandana Nandi  
Ms. Pamela Wilcox Hedin

#### **Ex-Officio Members**

Ms. Yvonne Green  
(CDC Office of Women's Health)  
Dr. Nancy Lee  
(HHS Office on Women's Health)  
Dr. Sabrina Matoff-Stepp  
(HRSA Office of Women's Health)  
Dr. Irene Sandvold (Health Resources  
and Services Administration)  
Dr. Stephen Taplin  
(National Cancer Institute/NIH)  
Dr. Richard Wild (Centers for  
(Medicare and Medicaid Services)

#### **Designated Federal Official**

Ms. Jameka Reese Blackmon, MBA, CMP  
Public Health Advisor, CDC/DCPC

#### **CDC Representatives**

Dr. Marcus Plescia, DCPC Director  
Ms. Jennifer Boehm  
Ms. Karen Boone  
Ms. Quanza Brooks-Griffin  
Ms. Georgina Castro  
Dr. Amy DeGroff  
Dr. Donatus Ekwueme

Ms. Alexandra Ehrlich  
Dr. Temeika Fairley  
Ms. Kristine Gabuten  
Ms. Nikki Hayes  
Ms. Kristy Joseph  
Ms. Patrice Kemp  
Dr. Teri Larkin  
Dr. Kimberly Leeks  
Ms. Gladys Lewellen  
Dr. Jacqueline Miller  
Mr. Mike Mizelle  
Ms. Alicia Ortner  
Ms. Melissa Palmer  
Ms. Patti Poindexter  
Ms. Michelle Poole  
Ms. Latasha Sanders  
Mr. Joel Stanojevich  
Ms. April Vance  
Ms. Faye Wong  
Ms. Brandie Yancy  
Ms. Debra Younginer

#### **Guest Presenters and Members of the Public**

Dr. Mary Dolan  
(Emory University School of Medicine)  
Ms. Kim Jones  
(Hologic Advocacy Department)  
Dr. Leighton Ku (George Washington  
University Medical Center Department of  
Health Policy)  
Ms. Citseko Staples-Miller  
(American Cancer Society-  
Cancer Action Network)

## ATTACHMENT 2

### Glossary of Acronyms

ACOs	Accountable Care Organizations
ACS	American Cancer Society
ACS-PUMS	American Community Survey Public Use Microdata System
BCC	Breast and Cervical Cancer
BCCAC	Breast and Cervical Cancer Early Detection and Control Advisory Committee
BRFSS	Behavioral Risk Factor Surveillance System
CAT	Cost Assessment Tool
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare and Medicaid Services
CRCCP	Colorectal Cancer Screening Program
DCPC	Division of Cancer Prevention and Control
EA	Evaluability Assessment
FPL	Federal Poverty Level
FQHCs	Federally Qualified Health Centers
FY	Fiscal Year
GWU	Georgia Washington University
HHS	Department of Health and Human Services
HMOs	Health Maintenance Organizations
HRSA	Health Resources and Services Administration
HSILs	High-Grade Squamous Intraepithelial Lesions
IOM	Institute of Medicine
LCAs	Local Coordinating Agencies (Wisconsin)
MDEs	Minimum Data Elements
NBCCEDP	National Breast and Cervical Cancer Early Detection Program
NCCDPHP	National Center for Chronic Disease Prevention and Health Promotion
NCI	National Cancer Institute
PSB	Program Services Branch
SSA	Systematic Screening Assessment
USPSTF	U.S. Preventive Services Task Force
WISEWOMAN	Well-Integrated Screening and Evaluation for Women Across the Nation
WWWP	Wisconsin Well Woman Program

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**BREAST AND CERVICAL CANCER  
EARLY DETECTION AND CONTROL ADVISORY COMMITTEE  
June 16-17, 2011  
Atlanta, Georgia**

**DRAFT Minutes of the Meeting**

The Department of Health and Human Services (HHS) and the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Division of Cancer Prevention and Control (DCPC), convened a meeting of the Breast and Cervical Cancer Early Detection and Control Advisory Committee (BCCAC). The proceedings were held on June 16-17, 2011 at the Westin Atlanta Perimeter North Hotel in Atlanta, Georgia.

**Opening Session: June 16, 2011**

**Amelie Ramirez, DrPH, MPH**

Director, Institute for Health Promotion Research  
University of Texas Health Science Center at San Antonio  
BCCAC Chair

Dr. Ramirez opened the floor for introductions. She verified that the voting members and *ex-officio* members in attendance constituted a quorum for BCCAC to conduct its business on June 16, 2011.

Dr. Ramirez called the meeting to order at 9:00 a.m. and welcomed the participants. The list of participants is appended to the minutes as Attachment 1.

## Program Services Branch Chief's Report

### **Faye Wong, MPH**

Chief, Program Services Branch, DCPC, NCCDPHP  
Centers for Disease Control and Prevention

Ms. Wong informed BCCAC that her Branch Chief's report would focus on changes, necessary improvements and the future direction of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). NBCCEDP was established in 1990 by Public Law 101-354, the Breast and Cervical Cancer Mortality Prevention Act of 1990. In 2010, CDC, its grantees and partners celebrated NBCCEDP's 20<sup>th</sup> anniversary and its numerous accomplishments in providing screening services to low-income, uninsured and under-insured women across the country.

CDC funds 68 Breast and Cervical Cancer (BCC) Programs in all 50 states, the District of Columbia, 12 American Indian/Alaska Native tribes and tribal organizations, and 5 U.S. territories. Since 1991, NBCCEDP grantees have screened >3.8 million women; completed >9.5 million breast or cervical cancer screening examinations; and detected 47,155 breast cancers, 130,645 pre-malignant cervical lesions (of which 42% were high grade), and 2,716 invasive cervical cancers.

The number of women screened by BCC Programs reflects the relatively flat funding level NBCCEDP has received from program year 2005 to 2009. Despite these budget constraints, program data show that NBCCEDP has been successful in identifying cancers, enrolling women into treatment and saving lives.

In addition to providing BCC screening, CDC also funds its grantees to conduct other services based on the public health model (e.g., case management, referrals, follow-up and support services; public information and education; professional development and education; quality assurance and quality improvement; and tracking, surveillance and evaluation). BCC Programs and NBCCEDP providers who detect cancers are able to refer women to state Medicaid programs for treatment under two laws: the Breast and Cervical Cancer Prevention and Treatment Act of 2000 and the Native American Breast and Cervical Cancer Treatment Technical Amendment Act of 2001.

To monitor compliance with NBCCEDP's public health components, CDC created quality indicators for each funded BCC Program to achieve (e.g., time between screening and diagnosis as well as time between diagnosis and treatment). These performance standards are linked to the level of funding CDC awards to each grantee.

NBCCEDP data quality indicators show that of all women with an abnormal breast screening test, 94% complete a diagnostic evaluation. Of these women, 91% complete a diagnostic

evaluation within 60 days. Of all women diagnosed with breast cancer, 97% initiate treatment. Of these women, 93% initiate treatment within 60 days.

Of all women with an abnormal Pap test, 91% complete a diagnostic evaluation. Of these women, 88% complete a diagnostic evaluation within 90 days. Of all women diagnosed with invasive cervical cancer or high-grade pre-malignant lesions, 92% initiate treatment. Of women with invasive cancer, 87% initiate treatment within 60 days.

Congressional appropriations for NBCCEDP increased from ~\$186 million in fiscal year (FY) 2009 to ~\$190 million in FY2011. However, the FY2011 funding level reflects a decrease of ~\$4 million from FY2010. CDC has made its program award recommendations for 2011-2012 based on the criteria of performance and equity.

CDC analyzed and compared Census data to the number of women screened by BCC Programs to generate an estimate for each state on the percentage of eligible women served. CDC also made strong efforts to ensure that the BCC Programs equitably “shared the pain” of NBCCEDP’s \$4 million cut in FY2011.

Based on these criteria, CDC recommended small increases to 4 grantees (e.g., small tribes and territories), level funding to 13 grantees (e.g., small programs and low-equity/high-performing programs), and reduced funding to 51 grantees. Based on its Congressional appropriation for NBCCEDP, CDC is only able to provide breast cancer screening to 12.5% of eligible women 40-64 years of age and cervical cancer screening to 8.5% of eligible women 18-64 years of age.

The Affordable Care Act was signed into law on March 23, 2010. CDC views the Affordable Care Act as a unique opportunity for prevention. Most notably, it includes the U.S. Preventive Services Task Force (USPSTF) recommendations of clinical preventive services, grades A and B, for coverage without cost sharing, deductibles or co-pays. The Affordable Care Act would provide more persons with access to health insurance and a source of payment for screening services.

The Affordable Care Act will cover BCC screening, but will not cover the other public health components of NBCCEDP (e.g., case management, referrals, follow-up and support services; public information and education; professional development and education; quality assurance and quality improvement; and tracking, surveillance and evaluation). CDC uses minimum data elements (MDEs) to track the number of women screened and the number of cancers detected in NBCCEDP, monitor trends and conduct research. CDC will use the MDEs and information on other program components to identify and prioritize the NBCCEDP services that should be continued in an era of health reform.

CDC identified several opportunities for public health to address existing challenges with cancer screening. To address financial barriers with deductibles and co-pays among uninsured and under-insured women, public health should increase efficiencies of programs and clinics,

leverage existing resources, and utilize the Affordable Care Act to eliminate deductibles and co-pays.

To address access to screening, eligibility for free or low-cost screening, and insurance coverage, public health should widely inform women of the necessity, importance and availability of screening, coverage of screening through a source of insurance, and opportunities to utilize existing benefits. Public health also should obtain broad input from women and address other barriers to accessing screening (e.g., cultural, language, literacy or transportation barriers).

To address the issue of utilizing preventive health screening services, public health should focus on whether women receive quality screening, full and timely follow-up of abnormal tests, timely referral into treatment, treatment regardless of insurance status, and tracking, follow-up and quality monitoring. Public health also should determine whether women return for screening according to guidelines.

In preparation of health reform, CDC launched a number of cancer screening promotion and demonstration projects to strengthen program capacity. CDC funded George Washington University to conduct a modeling study from 2010-2011 on the number of persons who will remain uninsured after the state insurance exchanges authorized in the Affordable Care Act are implemented in 2014. CDC will use results of the modeling study to determine the magnitude of potential changes in the NBCCEDP population and plan for the future.

CDC is conducting the NBCCEDP Waiver Demonstration Project from 2010-2012 with three grantees to gather data on a different budget distribution. BCC Programs are required by law to allocate 60% of their funds to clinical services and case management; a maximum of 10% of their funds to administrative costs; and the remaining 30% of their funds to other public health services (e.g., public information and education; tracking, surveillance and evaluation; quality assurance and quality improvement; and professional development and education). CDC will use results of the demonstration project to determine whether a budget distribution other than the current 60/40 provision split would be more helpful to BCC Programs in leveraging state funds and other resources to screen more women.

CDC is conducting the Promising Practices Assessment from 2010-2012 to compile best practices that have shown actual success or promise. CDC is conducting the NBCCEDP Care Coordination Project from 2010-2012 to identify approaches to extend care coordination and patient navigation activities to clinical settings that screen women without NBCCEDP dollars.

CDC is collaborating with the National Association of Chronic Disease Directors to fund two projects to strengthen relationships with Medicaid in terms of accessing data and increasing screening to Medicaid-eligible women. These projects will include Medicaid planning grants from 2010-2012 and Medicaid demonstration grants that will be launched in the future pending the availability of funds.

CDC initiated discussions with the Health Resources and Services Administration (HRSA) to explore the possibility of launching performance improvement initiatives in Federally Qualified Health Centers (FQHCs). FQHCs are an important source of care for NBCCEDP-eligible women because they serve low-income, diverse populations with many needs. The Affordable Care Act authorized substantial increased funding to expand FQHCs across the country.

CDC launched the Colorectal Cancer Control Program (CRCCP) in 2009, but the budget has not significantly increased since that time. CRCCP grantees are allowed to use 33% of their funds to pay for screening, but the remaining funds must be targeted to policy and systems changes and improved communications through small media, particularly evidence-based and successful interventions recommended in the CDC *Guide to Community Preventive Services*. CRCCP grantees also can use a portion of their funds to conduct “promising practices” activities so long as a rigorous evaluation component is included.

Ms. Wong concluded her Branch Chief’s report by noting that extensive discussion sessions were placed on the agenda for CDC to obtain advice from BCCAC on the potential impact of the Affordable Care Act on NBCCEDP’s current and future role, target populations, specific areas of focus and priorities. To assist BCCAC in providing guidance to CDC, she noted that several presentations would be made over the course of the meeting on the cancer screening promotion projects CDC has launched to prepare for and inform health reform.

**Richard Wild, MD, JD, MBA, FACEP**

Chief Medical Officer

Atlanta Regional Office, Centers for Medicare and Medicaid Services

BCCAC *Ex-Officio* Member

Dr. Wild provided additional details on the role of public health in health reform. The Affordable Care Act will expand health insurance coverage to several different areas in 2014. At this time, however, persons with pre-existing medical conditions can no longer be excluded from commercial health insurance coverage. The Affordable Care Act’s Pre-Existing Condition Insurance Plan is currently in effect and allows persons with a pre-existing condition or existing diagnosis who have been denied health insurance to be covered at standard group rate that is rated for “healthy people.”

At this time, 27 states operate individual “high-risk pools” in the Insurance Exchange Program. HHS administers health insurance plans in the remaining 23 states for persons with pre-existing conditions or diagnoses. All adult uninsured U.S. citizens and legal residents are eligible for the Affordable Care Act’s Pre-Existing Condition Insurance Plan.

Dr. Wild encouraged the BCCAC members to assist the Centers for Medicare and Medicaid Services (CMS) in widely publicizing the Affordable Care Act’s Pre-Existing Condition Insurance Plan to a diverse group of institutions, agencies, organizations, beneficiary and provider groups, and other non-traditional partners outside of Medicare and Medicaid programs.

Dr. Wild pointed out that CMS-developed materials on health insurance coverage for persons with pre-existing medical conditions or diagnoses were distributed to BCCAC for broader dissemination. Additional information on individual state plans also could be obtained from the [www.pcip.gov](http://www.pcip.gov) website.

## Overview of the NBCCEDP 60/40 Waiver Demonstration Project

### **Nikki Hayes, MPH**

Assistant Branch Chief, Program Services Branch, DCPC, NCCDPHP  
Centers for Disease Control and Prevention

Ms. Hayes presented an overview of the NBCCEDP 60/40 Waiver Demonstration Project. She reiterated that BCC Programs are required by law to allocate 60% of their NBCCEDP funds to direct service provision (e.g., screening, case management, certain patient navigation services, diagnostic follow-up and referral to treatment if necessary).

BCC Programs are prohibited from spending more than 40% of their NBCCEDP funds on non-screening components that support their infrastructures (e.g., public education and outreach; professional development and education; quality assurance and quality improvement; tracking, surveillance and evaluation; and partnership development).

The NBCCEDP Reauthorization Act of 2007 authorized CDC to approve up to five grantees to participate in a demonstration project that waives the current 60/40 requirement. Over the two-year project period from 2010-2012, three funded grantees will implement the waiver to leverage additional non-federal resources to increase screening rates while expanding their non-screening programmatic activities.

CDC recognized the need for the demonstration project because the existing 60/40 provision limits the ability of BCC Programs to effectively plan non-screening components (e.g., public education, outreach, professional development and quality assurance efforts). The 60/40 provision also limits the ability of BCC Programs to provide certain essential patient navigation services and restricts their flexibility and potential to extend the reach of their activities to increase screening.

CDC established criteria to select interested BCC Programs to participate in the 60/40 waiver demonstration project. Interested grantees had to show that the existing 60/40 provision created a barrier to enrolling NBCCEDP-eligible women. Additionally, grantees had to submit a plan to:

- demonstrate their capacity to leverage non-federal resources to increase current screening rates;

- document their ability to increase the number of women who receive NBCCEDP services (e.g., case management, patient navigation, and public education and outreach) regardless of the payment source;
- verify that implementation of the waiver would not adversely affect the quality of services and activities provided to clients; and
- describe their evaluation systems to monitor the quality of services and determine whether screening rates increased over the two-year project period.

The Massachusetts, Utah and Washington BCC Programs met the eligibility criteria and were approved as 60/40 waiver demonstration projects. Their screening program funding awards ranged from \$2.1-\$4.9 million in 2010 and they are not subject to the 60/40 requirement during the demonstration project period. The three grantees are conducting a diverse range of projects to support this effort.

The Massachusetts BCC Program expanded its Community Health Worker Train-the-Trainer Program to provide broader access to outreach, education and patient navigation activities to a newly-insured population. The Massachusetts universal healthcare program is the primary source for direct screening services, while CDC funds are the primary source for outreach, education and patient navigation services.

The Massachusetts BCC Program faced a major challenge in conducting the demonstration project. The ability to obtain endorsement from stakeholders and effectively collaborate with other entities in the state that provide the same services under the Massachusetts healthcare reform law has been difficult. However, these lessons learned will be valuable to Massachusetts at the state level and CDC at the federal level in terms of demonstrating the importance of the NBCCEDP infrastructure beyond the provision of direct screening services.

The Utah BCC Program expanded activities on multiple levels by launching the “Just Go” media campaign. The purpose of this effort is to increase breast cancer screening rates statewide with particular emphasis on women in rural and frontier areas of the state who previously were not screened. The media campaign includes advertisements in numerous venues (e.g., television, radio, magazines, newspapers, buses and the transit system) to raise public awareness of the importance of screening and inform women of available screening services in Utah.

The Utah BCC Program also held a number of focus groups to better understand the rationale for low screening rates among women in rural and frontier areas. Initial six-month data submitted by the Utah BCC Program showed that the media campaign led to an increase in the number of women in rural and frontier areas who received mammograms for the first time. The Utah BCC Program is using state funds to support direct service provision, while CDC has invested a great deal of resources to support the large-scale, multi-level media campaign.

The Washington BCC Program previously expanded its recruitment and outreach efforts by launching the “Ask Me” media campaign. This effort was piloted in 3 of the program’s 7 regions and led to successful screening of >1,700 additional women. The waiver demonstration project has allowed the Washington BCC Program to broaden the media campaign to all 7 regions and

particularly focus on reaching women of different racial/ethnic groups who previously were not screened. In year 2 of the demonstration project, the Washington BCC Program will modify its existing campaign materials to include messages to insured men and women to learn more about breast, cervical and colorectal cancer screening.

To support the three grantees over the two-year project period, CDC is providing ongoing technical assistance and consultation; monitoring program data collection and analysis; offering guidance for quality assurance; and evaluating the three demonstration projects to inform national program planning in the future.

Ms. Hayes concluded her overview by emphasizing that the 60/40 Waiver Demonstration Project will allow CDC to address the concerns of grantees at the program level and explore other opportunities to expand the reach of NBCCEDP at the national level. CDC is responsible for reporting the results of the demonstration project to Congress and making recommendations on next steps.

At the conclusion of Ms. Hayes' overview, BCCAC engaged in an open discussion. At that time, BCCAC expressed a great deal of concern about the possibility of Congress eliminating NBCCEDP. Because Congress is significantly reducing or entirely eliminating programs to reduce the federal debt, some BCCAC members believed that the Affordable Care Act could be the sole source for women to receive breast and cervical cancer screening in the future.

BCCAC made a number of comments and suggestions for CDC to consider in its ongoing implementation of the 60/40 Waiver Demonstration Project and the future direction of NBCCEDP.

- CDC should closely collaborate with the American Cancer Society (ACS) and other partners to educate policymakers on the critical need to continue funding NBCCEDP despite health reform. NBCCEDP has been in existence for 20 years, but is still only able to provide breast cancer screening to 12.5% of eligible women and cervical cancer screening to 8.5% of eligible women. The Affordable Care Act will provide more persons with access to health insurance, but large segments of the population still will not be covered.
- CDC should establish additional goals for the demonstration project beyond increasing screening rates. Goal 1 would be for the three BCC Programs to create linkages to primary care and other entities that provide screening to develop integrated systems rather than independent parallel systems. The BCC Programs should focus on interoperability by using NBCCEDP data, patient reminders and tracking systems to connect to primary care. Goal 2 would be for CDC to encourage the three BCC Programs to build capacity for the demonstration project to serve as an organized screening program that includes quality assurance, tracking and surveillance.
- CDC should partner with accountable care organizations (ACOs) to have BCC Programs accountable for screening their populations. This approach would motivate BCC Programs to strengthen collaborations with other screening programs to increase screening rates.

- CDC should conduct a study to show the population of women who will not receive breast and cervical cancer screening under the Affordable Care Act. These subgroups include women who will be unable to afford the Affordable Care Act, women who will opt-out of the Affordable Care Act, and women who will be ineligible for the Affordable Care Act due to their citizenship status.
- CDC should rigorously evaluate the quality of the overall demonstration project by measuring the reach of the three individual projects to the population as a whole and tracking the proportion of persons who utilize the full range of services (e.g., screening, follow-up, diagnosis and referral to treatment). The proportion of the population screened by NBCCEDP should be used as a quality measure in the evaluation. CDC should present the evaluation results to Congress to show the effectiveness of the demonstration project and emphasize the continued need for NBCCEDP. Although the Affordable Care Act will provide more persons with access to health insurance and a source of payment for screening services, NBCCEDP's role as an organized screening program with quality measures must be sustained.
- CDC should conduct a cost-effectiveness study to present a strong case to Congress regarding the success of NBCCEDP's 40% non-screening activities (e.g., promotion of screening, quality measures, public education and outreach) in reducing late-stage disease.

## Overview of the NBCCEDP Promising Practices Assessment

### Kimberly Leeks, PhD, MPH

Health Scientist/Evaluator, Program Services Branch, DCPC, NCCDPHP  
Centers for Disease Control and Prevention

Dr. Leeks presented an overview of the NBCCEDP Promising Practices Assessment. CDC heavily relies on the *Guide to Community Preventive Services* to identify evidence-based practices because this credible resource is based on a scientific systematic review process. CDC has tested and promoted various approaches (e.g., best practice studies, success stories and promising practices) to identify effective practices. However, the level of rigor and underlying evidence base across these approaches are inconsistent and can be poorly defined.

CDC is using the Systematic Screening Assessment (SSA) method to conduct the NBCCEDP Promising Practices Assessment. This method is designed to bridge the gap between "promising" and "evidence-based" practices. The overarching goal of the SSA method is to identify and screen a high volume of real-world interventions to select those that are ready for evaluation or highly promising in terms of their plausible effectiveness, reach to the target population, feasibility and capacity to be generalized to other settings.

To achieve this goal, the SSA method informs the field about prevalent practices; provides constructive feedback and technical assistance to public health innovators; establishes a foundation to evaluate the effectiveness of practice-based innovations and disseminate models

for adoption; and sequences the existing evaluability assessment (EA) and expert judgment evaluation methods.

The CDC Division of Nutrition, Physical Activity and Obesity collaborated with the Robert Wood Johnson Foundation to develop the SSA approach that integrated an expert peer review with an EA. In this effort, candidate practices and sites were identified and 30 EAs were completed. The CDC Division of Heart Disease and Stroke Prevention implemented a modified version of the SSA approach to identify promising field-based practices among state health department grantees. Both divisions found the approach to be quite effective.

The goals of the NBCCEDP Promising Practices Assessment are four fold: identify promising practices that increase population-level screening for breast and cervical cancer detection for rigorous evaluation, understand current practices, bridge the gap between promising and evidence-based practices, and prepare for the health reform environment. The SSA results will inform CDC's programmatic efforts and evaluation planning; provide important information about strong public health practices that are feasible for practice-based implementation and best prepared for more rigorous program evaluation; and offer a valuable opportunity to provide feedback and technical assistance to programs about practices assessed under the study.

Phase I of the study is underway. CDC is currently conducting the SSA process to identify promising interventions and practices implemented by NBCCEDP grantees and others in the program areas. In Phase II, CDC plans to rigorously evaluate the effectiveness of the program based on the availability of resources. The six steps of the SSA method are described below.

Step 1 is the selection of priority areas for assessment. Due to the future of NBCCEDP and the emphasis on population-based approaches, CDC selected three content areas for the study: health education and promotion; case management and patient navigation; and quality assurance, quality improvement and professional development.

Step 2 is the solicitation of programs and interventions and the nomination process. CDC developed specific inclusion and exclusion criteria to identify and define "promising" practices. To be included in the study, programs and interventions had to be implemented for at least 6 months and be suitable for implementation and replication in similar settings or populations. Programs and interventions also had to demonstrate programmatic and design integrity and promise by their reputations. Programs and interventions with a history of a rigorous outcome and impact evaluation were excluded from the study.

CDC hosted a webinar and used listservs to issue a call to BCC Programs and their partners in December 2010-January 2011 to nominate the practices of NBCCEDP grantees, other CDC-funded programs, sub-awardees and other grantee partners for inclusion in the study. CDC reviewed the nominations, applied the eligibility criteria, and obtained additional information from program staff on reach, program implementation and data collection efforts. Of the 98 nominations that were submitted, 53 were submitted to the expert panel for further review based on several key factors, particularly existing partnerships, uniqueness and innovativeness

A number of factors resulted in 45 nominations being excluded from the study. For example, the practice (e.g., distribution of an educational DVD or calendar) was not plausible for impacting screening prevalence and adherence to diagnostic follow-up for breast and cervical cancer. The practice was rigorously evaluated and published in a journal. The practice was a replication of a national program. The practice had a history of high staff turnover.

Step 3 is the initial review of programs and interventions by an expert panel. CDC held the expert panel in April 2011 with representation by 22 federal partners, state grantees, community-based organizations, academic institutions and non-profit organizations. The expert panel is a group of nationally recognized subject-matter experts and practitioners with extensive experience in breast or cervical cancer screening in one of the three content areas: evaluation, measurement of health outcomes, and minority health and health disparities. The expert panel judged the practices based on their plausibility, feasibility, appropriateness and readiness for evaluation.

The expert panel screened and rated the initial list of 53 practices through a blinded review process based on the following criteria: potential impact, reach to the target population, acceptability to stakeholders, feasibility of implementation and adoption by similar organizations, capacity to be transported or generalized, sustainability of the intervention and health effect, and staff and organizational capacity. Of the practices prioritized for EAs, the expert panel selected 16.

To select six practices for the health education and health promotion content area, the expert panel considered whether the practice was a population-based or individual-based intervention, if the practice was innovative or a replication of an evidence-based intervention, and if the practice had strong community partnerships. One of the six selected practices, TEAM UP: “Cooking for a Lifetime” Cancer Cooking Schools, offers healthy cooking classes with a focus on the African American population. Breast screening information is distributed during the cooking classes.

To select five practices for EAs in the quality assurance, quality improvement and professional development content area, the expert panel considered whether the practice was innovative in terms of timeliness in the use of data, pay for performance in the context of NBCCEDP, and implementation in different settings. The expert panel also considered whether the practice had a wealth of partnerships.

During the site visits to conduct the EAs, the expert panel emphasized the need to learn more about processes and approaches used by staff to implement activities. One of the five selected practices, the Utah Cancer Control Program Database Project, designed a database that flags the names of women who are due or past due for screening.

To select six practices for the case management and patient navigation content area, the expert panel considered the holistic definition of case management over the course of prevention, screening, early detection and treatment. The expert panel’s difficulty in estimating the amount

of resources needed to implement these practices has implications on the ability to replicate the practice.

The expert panel also considered whether the practice was responsive to other needs of the target population (e.g., translation services, mobile mammography and assistance with administrative paperwork). One of the six selected practices, Asian Breast Care for Asian American Women, developed a case management and patient navigation project that guides women through the screening process.

Step 4 is implementation of the EAs for the selected programs and interventions. CDC contracted ICF Macro to conduct site visits to BCC Programs in June-September 2011 to conduct the EAs. The purpose of the EAs will be to elicit a program description, including a logic model and theory of change. CDC will use the EA results to answer two primary questions. Does the practice have a plausible program theory that supports its effectiveness? Is the practice ready to be evaluated in terms of implementation with fidelity and availability of data?

Prior to conducting the EAs, ICF Macro will review program documents, develop a logic model and review existing models. During the 2.5-day site visits to conduct the EAs, ICF Macro will interview staff and stakeholders with an interest in the practice, document implementation of the practice, revise the logic model to reflect realities in the field, review preliminary findings and discuss potential evaluation questions of interest with staff and stakeholders, and offer technical assistance on the logic model and data collection efforts of the practice. After completing all of the EAs, ICF Macro will produce and submit a summary report to CDC.

Step 5 is the review and rating of programs and interventions that show promise or readiness for evaluation. CDC will reconvene the expert panel in December 2011 to identify practices that are most promising for population-level impact and most ready for formal, in-depth and rigorous evaluation. The EA reports will be used to review practices and reduce uncertainty. The expert panel will produce its ratings and reports of practices and develop a list of practices that are ready for outcomes-focused evaluation.

Step 6 is the use of information. The study results will be used to position promising practices for rigorous evaluation, provide constructive feedback to refine interventions to the practices, and synthesize findings.

CDC's lessons learned to date in conducting the NBCCEDP Promising Practices Assessment include the critical role of project officers in obtaining 98 nominations, the need to schedule the call for nominations to avoid competing priorities, the importance of engaging the Program Directors' Council as an advisor to the study, and the need to extensively educate outside contractors on the history of NBCCEDP.

Dr. Leeks concluded her overview by asking BCCAC to provide input on two key questions during its discussion. First, what resources, tools and products can be created for grantees that were not selected for EAs to promote evaluation readiness? Second, if funding is not available

for an evaluation of the selected practices, what tools, resources and products can be provided to the BCC Programs that participated in the EAs to sustain their evaluation efforts?

Dr. Ramirez confirmed that during its open discussion on the future direction of NBCCEDP in an era of health reform, BCCAC would consider the specific questions Dr. Leeks proposed. In the interim, the BCCAC members made two key suggestions for CDC to consider in its ongoing implementation of the NBCCEDP Promising Practices Assessment.

- CDC should ensure that the subject-matter expertise of the expert panel extends beyond the technical aspects of breast and cervical cancer care to include the role of organizational structures and environments in helping, harming or facilitating processes of care. The study should be designed with indicators of context to measure team function and organizational functionality.
- Some BCCAC members were disappointed about the minimal number of cervical cancer screening practices included in the study. CDC should ensure that the study is designed to highlight fundamental differences between and approaches to breast and cervical cancer screening.

### Overview of the NBCCEDP Patient Care Coordination Demonstration Project

#### **Kristine Gabuten, MPH, CHES**

Program Services Branch, DCPC, NCCDPHP  
Centers for Disease Control and Prevention

#### **Amy DeGross, PhD, MPH**

Program Services Branch, DCPC, NCCDPHP  
Centers for Disease Control and Prevention

Ms. Gabuten and Dr. DeGross presented CDC's national perspective of the NBCCEDP Patient Care Coordination Demonstration Project. The overarching goal of the project is to demonstrate new roles for state health departments in the early detection of breast and cervical cancer through targeted outreach, patient navigation and case management.

CDC established two key objectives to achieve the project goal. Changes in operational systems, policies or practices would be created and implemented to improve coordination of cancer prevention and early detection activities. Existing patient navigation and case management activities would be extended to larger health settings to provide these essential services to additional program-eligible women who are not currently covered by NBCCEDP-funded services.

CDC funded 11 Care Coordination Program grantees in Alabama, Colorado, Connecticut, Louisiana, Maryland, New Jersey, New York, South Dakota, Texas, Virginia and Wisconsin to participate in the demonstration project with awards ranging from \$160,000-\$250,000. The

geographic reach of the grantees includes 1 city, 3 counties, 5 regions, 2 states and 1 Indian reservation. The geographic reach of Maryland covers both a city and county.

The characteristics of populations targeted in the study include NBCCEDP-eligible women, women in certain racial/ethnic groups (e.g., African American, Hispanic, Vietnamese and American Indian women), and women in rural areas of the country. For example, the South Dakota program targets American Indian women and women in rural areas.

The grantees identified several common barriers to women accessing services, such as geographic, financial, education, and language and cultural barriers. Additional barriers include fear, environmental issues and negative past experiences. For example, the Louisiana program determined that the aftermath of Hurricane Katrina prevented many women from presenting for services.

The grantees are providing services in diverse settings, including FQHCs, community clinics, county health departments, hospitals, university health systems and urban Indian health clinics. For example, the University Health System in San Antonio and the Parkland Health and Hospital System in Dallas serve as the Texas program's primary sources for services. These health systems are components of large and well-established networks and are able to reach diverse populations.

In year 1 of the demonstration project, the grantees recruited staff, built partnerships, developed data systems, and trained patient navigators through established programs, new or existing curricula and patient navigation toolkits. For example, the New Jersey program used the Harold P. Freeman Institute to train FQHC staff to serve as patient navigators; partnered with the New Jersey Medical Assistance Program and the ACS Eastern Division; and created a modified version of the CaST system to add performance measures and standardized queries to assess program performance.

CDC drafted a logic model to provide grantees with a strategic planning tool to evaluate measurable outcomes. At the infrastructure and systems level, grantees are expected to collaborate with new healthcare providers and provide support to systems and policy changes within healthcare delivery systems. At the patient navigator level, grantees are expected to recruit, employ and train new patient navigators.

At the service delivery level, grantees are expected to impact patient-level outcomes by focusing on patient outreach and recruitment, conducting patient assessments to identify barriers to screening, providing patient education to resolve barriers, performing tracking and follow-up, and collecting and reporting data. For each of these activities, CDC specified immediate outputs, short-term outcomes to achieve in <2 years, intermediate outcomes to achieve in 2-5 years, and long-term outcomes to achieve in  $\geq 5$  years.

CDC provided the grantees with examples of process measures to track during the demonstration project and potential sources to collect these data. For the infrastructure and systems level, for example, grantees could use program records to track the number and types

of healthcare settings where patient navigators are placed. For the patient navigator level, grantees could use staff records to track the number and types of patient navigators who were hired or moved to the Care Coordination Program.

For the service delivery level, grantees could use program records to track the number and types of outreach and recruitment activities and the number of persons recruited for navigation. In addition to examples of process measures, CDC also provided the grantees with potential short-term outcome measures that are consistent with the logic model.

CDC encouraged the grantees to adopt a set of proposed performance measures as part of their care coordination efforts during the demonstration project. For the infrastructure and systems target, for example, operational and policy changes that improve coordination of breast and cervical cancer screening and diagnostics care should be described. For the patient navigation target, the percentage met of the annual projection for the number of patients to be enrolled, assessed and navigated should be >80%.

For the patient assessment target, the percentage of patients enrolled in navigation services who received a formal assessment to identify patient barriers and needs should be >95%. For the clinic screening prevalence target, the percent of age-eligible patients within the clinic census who are up-to-date on breast and cervical cancer screening should be >80%. Of the 15 proposed breast and cervical cancer diagnostic measures, 11 are performance measures that CDC currently utilizes to track NBCCEDP activities.

CDC program consultants and the Care Coordination Workgroup are continuing to provide ongoing technical assistance and consultation to provide an opportunity for all grantees to obtain guidance on their evaluation plans and discuss issues related to data access. CDC also is offering project-specific resources through networking events, webinars and listservs for grantees to share resources, tools and other information.

CDC identified several challenges in the demonstration project. Most grantees were required to collaborate with new sources or develop new databases to access data for the evaluation planning component. CDC recognizes that limited access to data and the provision of quality services might be problematic if larger health settings pay for screening services for NBCCEDP-eligible women. Delays in hiring staff and issuing contracts resulted in longer start-up times than anticipated for the grantees to implement their projects.

**Gale Johnson, MPA**

Director, Wisconsin Well Woman Program  
Wisconsin Department of Health Services  
BCCAC Member

Ms. Johnson presented Wisconsin's grantee perspective of the NBCCEDP Patient Care Coordination Demonstration Project. The Wisconsin Well Woman Program (WWWP) provides breast and cervical cancer screening to low-income, uninsured and under-insured women who are 35-64 years of age and with incomes 250% below the Federal Poverty Level (FPL). Well

Woman Local Coordinating Agencies (LCAs) in 71 counties and 11 tribes enroll women in WWWP through participating healthcare providers. Because Milwaukee County is the largest county in the state and accounts for a population of >1 million persons, the Suburban Milwaukee and City of Milwaukee Coordinating Agencies are used to enroll women in WWWP rather than one LCA.

LCAs use a simple one-page enrollment form that only requires women to provide proof of their age, income and insurance status. In addition to enrollment, LCAs also are responsible for outreach and public education, eligibility determination, case management and provider support. The three major components of WWWP are the LCAs, a statewide network of >1,100 provider sites and program partners. WWWP has provided breast and cervical cancer screening services to >62,000 women since 1994.

Wisconsin is one of 11 grantees that CDC funded to conduct the NBCCEDP Patient Care Coordination Demonstration Project. Wisconsin proposed to use WWWP to demonstrate that NBCCEDP is well positioned for emerging changes in the healthcare delivery system by focusing on the value of its non-screening components. Wisconsin designed its project to demonstrate the efficacy of integrating existing NBCCEDP case management and patient navigation activities into larger healthcare provider systems to eliminate barriers to breast and cervical cancer screening and benefit a larger population beyond WWWP-eligible women.

Wisconsin focused the urban component of its project on the Southeastern public health region of the state. A partnership was established with the University of Wisconsin-Milwaukee College of Nursing to provide training for community health workers and conduct targeted outreach, patient navigation and case management.

Wisconsin focused the rural component of its project on the Northern, Central and Western public health regions of the state. A partnership was established with the Marshfield Clinic to implement a patient navigation program. Wisconsin decided to target two populations in the demonstration project: WWWP-eligible women and low-income women who might be ineligible for WWWP. Ms. Johnson presented the new enrollment form that Wisconsin specifically developed for the demonstration project. The form offers several resources to refer WWWP-ineligible women to other programs, but Wisconsin maintains information on these women in its database for tracking purposes.

Wisconsin is using WWWP to conduct a host of activities during the demonstration project:

- provide culturally-appropriate and targeted outreach to women 35-64 years of age in the Southeastern region;
- arrange for translation or interpretation services, particularly for Hispanic and Hmong populations;
- implement small-group and one-on-one educational strategies in non-traditional and informal settings (e.g., Laundromats, private homes, churches and social gatherings) to inform women of their breast and cervical cancer screening options, particularly for Hispanic populations;

- provide education that focuses on increasing awareness of recommended breast and cervical cancer screening, particularly for African American and Hispanic populations;
- conduct follow-up telephone calls to provide additional information and resources to women who need social support beyond screening (e.g., transportation and child care);
- identify NBCCEDP-eligible women and collaborate with appropriate LCAs to ensure these women receive screening, diagnostic and treatment services as needed;
- provide outreach to low-income women who are ineligible for NBCCEDP and link these women to other resources for screening, diagnostic, treatment and support services;
- collaborate with parish nurses to more effectively reach women in rural areas; and
- link women and their families with support services that are available through other organizations.

Ms. Johnson concluded her overview by highlighting the goals Wisconsin established for the demonstration project for the period of September 30, 2010 to June 29, 2011. Targeted outreach on the importance of breast and cervical cancer screening will be provided to 1,000 low-income, uninsured women living in Southeastern Wisconsin. A patient navigation program will be implemented focusing on women living in rural areas in Northern, Central and Western Wisconsin.

Appropriate breast and cervical cancer screening services will be provided to at least 150 women as a result of the demonstration project. A series of training programs will be developed for patient navigators and community health workers. A report will be produced with demographic data on women who received patient navigation services regardless of the payment source. The impact of the demonstration project in Wisconsin will be evaluated.

BCCAC made several suggestions for CDC to consider in further implementation of the NBCCEDP Patient Care Coordination Demonstration Project.

- CDC should partner with the National Cancer Institute (NCI) on its ongoing project to create an infrastructure to measure activities in community settings. The CDC/NCI collaboration could play a critical role in developing common and standardized measures for breast, cervical and colon cancer services.
- CDC should ensure that its measures for the demonstration project are appropriately defined. For example, the “process” measures appear to be “structural” measures, while the “outcome” measures appear to be “process” measures. CDC should gather and use data from other sources (e.g., Medicare and managed care organizations) to compare measures of the demonstration project to other programs and evaluate the quality and effectiveness of the project after making appropriate adjustments for differences in populations.
- CDC should ensure that the patient navigation and patient recruitment components of the demonstration project are not limited to collecting data on the number of women who were recently screened for breast or cervical cancer. A sole focus on reaching and collecting data on women who were recently screened for breast or cervical cancer will result in a disservice to NBCCEDP’s role as a national public health program. CDC

should add a new measure to the demonstration project for grantees to reach and collect data on rarely or never screened women.

- CDC should review the European guidelines because this evidence base serves as a rich data source on the development of standards for process measures and the value of programmatic evaluation.
- CDC should ensure that grantees strengthen collaborations with other providers to enhance access to data and tracking of screening outcomes to inform evaluation of activities.

## Division of Cancer Prevention and Control Director's Report

### **Marcus Plescia, MD, MPH**

Director, Division of Cancer Prevention and Control  
Centers for Disease Control and Prevention

Dr. Plescia covered the following topics in his Director's report to BCCAC. The United States is currently facing uncertainty and significant changes, particularly an austere political and fiscal environment, changing demographics in society, new technologies and an epidemic of chronic disease.

Congress passed the FY2011 Federal budget that included CDC's appropriation in May 2011. The reduction in CDC's base budget by \$740 million reflects a cut of >11% from the FY2010 appropriation level. The FY2011 appropriation is CDC's lowest base budget since FY2003. Congressional language directed CDC to make \$200 million in specific reductions. CDC obtained guidance from HHS and the Office of Management and Budget to identify an additional \$500 million in targeted programmatic reductions and >\$60 million in administrative savings.

At the division level, DCPC's FY2011 budget of ~\$345.3 million reflects a substantial reduction of ~\$20 million. All of DCPC's programmatic line items received funding decreases, while Johanna's Law and the Geraldine Ferraro Cancer Education Programs were entirely eliminated. NBCCEDP sustained a budget reduction of \$4 million. DCPC is concerned because further budget reductions to its cancer programs are expected in FY2012.

Despite these severe budget cuts, positive changes have occurred in fiscal allocations and resources at other levels. CDC recently announced that the Public Health Prevention Fund would be used to award Chronic Disease Capacity Building Grants to states. Each state is expected to receive an award of ~\$700,000-\$800,000 to increase its efficiency and strategic approaches to addressing chronic diseases.

CDC also announced that the Public Health Prevention Fund would be used to award Community Transformation Grants for communities and states to target chronic disease prevention and primary risk factors. These new dollars present exciting opportunities for states and communities to conduct new and innovative projects to make further progress in physical

activity and nutrition, tobacco, alcohol use and vaccination to prevent long-term cancers. Although these grants will not directly focus on cancer screening, the funded projects will have a significant impact on reducing the U.S. burden of cancer.

In 2010, CDC began issuing monthly *Vital Signs* reports that serve as a call to action to highlight data and trends, and outline strategies to address an important public topic. The first *Vital Signs* featured a report by DCPC: "Surveillance of Screening-Detected Cancers (Colon and Rectum, Breast and Cervix): United States 2004-2006." DCPC's follow-up surveillance report in July 2011 will highlight colorectal cancer.

The surveillance report emphasized the need to scale-up cancer screening in the United States. Mammography screening rates in the United States have not improved since 2002. At this time, 7 million women 50-74 years of age need to be screened for breast cancer and 22 million adults 50-74 years of age need to be screened for colorectal cancer.

Insured persons are twice as likely to be screened as uninsured individuals. Data collected in 2008 from the CDC Behavioral Risk Factor Surveillance System (BRFSS) showed that mammography screening rates were 81.6% among insured persons and 54.3% among uninsured persons. Colorectal screening rates were 64.7% among insured persons and 34.3% among uninsured persons.

DCPC's surveillance report further emphasized that preventable cancers are not being diagnosed when treatment is most effective. At this time, ~50% of colorectal and cervical cancer cases and 33% of breast cancer cases in the United States are diagnosed at late stages of the disease.

The Affordable Care Act will provide health insurance coverage and address quality and cost; it also will present a true opportunity for public health. The four public health pillars of the Affordable Care Act will be valuable to cancer control and cancer screening. Preventive services will be offered without cost sharing. A wide range of other Affordable Care Act policies and programs will have an impact on the burden of cancer. The Prevention and Public Health Fund was used to award new dollars to state and local health departments and communities to focus on chronic diseases. The National Prevention Strategy will be implemented as a result of new dollars from the Prevention and Public Health Fund.

At the agency level, CDC recognizes that the Affordable Care Act could decrease its role in providing and paying for screening services. At the division level, DCPC is examining the current role of NBCCEDP and has started to address key issues in the context of the Affordable Care Act. DCPC has discussed the unique contributions of NBCCEDP, challenges NBCCEDP currently addresses, areas where NBCCEDP excels, and best practices and specific aspects that make NBCCEDP unique from any other program.

DCPC also has considered additional questions during its internal discussions. What activities should DCPC phase out of or phase into its existing program model? If CDC designed NBCCEDP in 2011 rather than in 1990, what program components would be different? During

the open discussion on the role of NBCCEDP in the context of the Affordable Care Act, Dr. Plescia confirmed that CDC would solicit BCCAC's guidance on these issues and questions.

To plan for health reform and shift to a new direction in public health and cancer screening, CDC has launched a number of cancer screening special projects with a five-year project planning period of 2009-2014. Dr. Plescia noted that presentations on four of the special projects (e.g., the NBCCEDP 60/40 Waiver Demonstration Project, NBCCEDP Promising Practices Assessment, NBCCEDP Patient Care Coordination Demonstration Project, and George Washington University Modeling Study) were placed on the agenda to guide BCCAC's discussions.

CDC's development of the NBCCEDP MDE system has been outstanding and unique in terms of its systematic approach to quality assurance. As NBCCEDP makes the transition to health reform, however, CDC is aware of the need to review other program models with a track record of success and compile lessons learned. These models include infectious disease public health approaches as well as domestic and international organized screening programs. CDC also recognizes the need to adapt the NBCCEDP MDE system to be useful to new systems and approaches to provide care in an era of health reform.

The future direction of cancer screening will be based on traditional public health components of outreach, care/case management, quality assurance/quality improvement and organized approaches. The case management component of the public health model has a history of effectiveness in enrolling persons in healthcare systems for screening, assuring adequate follow-up, providing patient navigation services, and making referrals for treatment when necessary. However, case management should be expanded to focus on practice-based outreach, disparate populations and case management.

The quality assurance/quality improvement component of the public health model is a critical part of NBCCEDP and a source of pride for CDC. CDC published a paper in December 2009 in the *American Journal of Public Health* on the "Timeliness of Breast Cancer Diagnosis and Initiation of Treatment in NBCCEDP: 1995-2005." The MDE system was designed to track the quality of services that funded BCC Programs provide to their clients. The MDE system should be adapted and applied to other healthcare systems.

The organized approaches component of the public health model focuses on a broader societal approach to cancer screening in the United States. The National Health Service in the United Kingdom has responsibility for assuring the population is screened for breast, cervical and colorectal cancers. The U.K. system is well organized, maintains patient records, distributes patient reminders, and tracks the outcomes of patients with positive screening results.

The 1999 Quinn, *et al.* study reported a dramatic decrease in invasive cervical cancer rates and a tremendous increase in coverage of Pap smears after the National Call-Recall System was introduced in the United Kingdom in 1987. Replication of this model in the United States would allow public health to provide leadership for population-based screening. For example, CDC, a

state health department or another centralized public health agency could be responsible for distributing screening reminders to patients.

CDC will take advantage of two new opportunities to apply a more organized approach to cancer screening. First, CDC has existing relationships with FQHCs to offer NBCCEDP-funded screening services to women. Increased funding through the Affordable Care Act will enable FQHCs to nearly double the number of patients seen over the next 5 years. CDC is currently exploring strategies to leverage a portion of the FQHC investment to support NBCCEDP services. Collaborative activities with FQHCs will include expanding the use of cancer screening performance indicators, outreach workers and patient navigators, and electronic health records.

Second, expanded coverage in health reform will yield solid growth among persons covered through Medicaid. CDC will respond to this new opportunity by enhancing current partnerships through collaborative agreements with state Medicaid programs. The partnerships will be used to focus on policy development, planning and development of data registries and linkages, and development and implementation of outreach demonstration projects.

CDC is collaborating with the National Association of Chronic Disease Directors to fund two projects to strengthen relationships with Medicaid in terms of accessing data and increasing screening to Medicaid-eligible women. These projects will include Medicaid planning grants and Medicaid demonstration grants.

Dr. Plescia concluded his Director's report by asking BCCAC to provide feedback in two major areas. In terms of key partners for NBCCEDP, BCCAC should consider gaps in current partnerships, strategies to capitalize on existing partnerships, and new opportunities to leverage NBCCEDP's current network. In terms of challenges for NBCCEDP, BCCAC should consider challenges that will be addressed by health reform, persistent challenges, and new, emerging challenges when the Affordable Care Act is implemented.

BCCAC advised CDC to issue specific guidance to its NBCCEDP grantees to partner with state Medicaid programs. A recommendation from CDC could help to minimize or eliminate difficulties BCC Programs encounter in their efforts to access Medicaid data.

### **BCCAC Open Discussion: Session 1**

Dr. Ramirez opened the floor for BCCAC's open discussion on the role of NBCCEDP in the context of the Affordable Care Act.

- 1. What is your perspective of the Affordable Care Act? For example, what Affordable Care Act-related activities are your agencies, institutions or organizations currently conducting? What is the potential impact of the Affordable Care Act on your agencies, institutions or organizations? What is your existing knowledge or concerns about the Affordable Care Act?*

- **Sabrina Matoff-Stepp, PhD:** Dr. Matoff-Stepp reported that HRSA received billions of new Affordable Care Act dollars to expand the existing FQHC network with additional sites to provide more care to uninsured and under-insured populations. BCCAC should provide advice to CDC on leveraging the network of providers in the HRSA-funded National Health Service Corps for NBCCEDP. In return for loan repayments, providers in this program make a commitment to provide services to hard-to-reach, disproportionately-impacted or marginalized communities. The Affordable Care Act legislatively mandated Offices of Women Health in federal agencies for the first time. The HRSA, CDC and HHS Offices of Women Health are represented on BCCAC and could serve in an overarching and coordinating role for outreach and education. The Affordable Care Act designated HRSA with responsibility for developing *Women's Health Preventive Guidelines*. Preventive services that are not ranked as USPSTF A/B recommendations would be covered in the guidelines. HRSA and its partners commissioned the Institute of Medicine (IOM) to convene an expert committee to conduct a study and formulate evidence-based recommendations to inform the development of the guidelines. The report will be completed in July 2011, submitted to HHS Secretary Kathleen Sebelius for review, and released to the public on August 1, 2011. If the HHS Secretary approves the recommendations, all health insurance companies will be required to adopt the guidance as a women-specific set of standard preventive services. During controversial public meetings, organizations and other stakeholders most frequently advised the IOM to recommend well woman care, violence screening in primary care, and contraception in its report. The IOM also was charged with providing recommendations on keeping the guidelines up-to-date as science and evidence evolve over time. Dr. Matoff-Stepp confirmed that she would provide BCCAC with more information on HRSA's new *Promotoras* Program to determine if this initiative could play a role in NBCCEDP's recruitment and case management activities.
- **Evan Myers, MD, MPH:** Dr. Myers reported that Duke University Medical Center is concerned about the potential adverse impact of the Affordable Care Act on the incomes of academic physicians and clinicians in other settings. Moreover, the complexities of the Affordable Care Act might adversely affect both the clinical practice and administrative business components of medical centers. A compelling paper was recently published in the *New England Journal of Medicine* regarding the inequality of insurance coverage in terms of the ability of persons to access physicians. Although the Affordable Care Act will provide health insurance to more individuals, disparities in access will continue to exist.
- **Hannah Linden, MD:** Dr. Linden reported that the University of Washington funds an academic medical center and a county hospital to provide healthcare services to patients. The Affordable Care Act is expected to improve the budget of the county hospital and adversely impact the budget of the academic medical center. The academic medical center is currently identifying strategies to become more efficient in a health reform environment. Services will need to continue to be provided to undocumented persons and more investments will be needed in electronic tracking mechanisms.

- **Pamela Wilcox Hedin, RN:** Ms. Hedin reported that the American College of Radiology is concerned about the adverse impact of the Affordable Care Act on its membership. The role of mammographers and other radiology professionals in ACOs is uncertain at this time. The ability of ACOs to measure the performance of radiology professionals is unknown as well. Decisions have not been made to date on whether radiology professionals should be a part of or separate from ACOs.
- **Amelie Ramirez, DrPH, MPH:** Dr. Ramirez reported that the University of Texas Health Science Center at San Antonio is exploring strategies to more rapidly produce primary care physicians. A model of condensing the traditional 8-year program to a 7-year program is being tested at this time.
- **Vivien Hanson, MD:** Dr. Hanson is retired and now serves as a private consultant. She provided input based on her vast experience in two federally-funded programs: family planning and NBCCEDP. She did not view the Affordable Care Act as a “universal healthcare” system. She also expressed concern about persons that the Affordable Care Act will overlook. Most notably, the Seattle-King County Health Department no longer provides immunizations and has closed 3 of its 10 family planning clinics. The role of nurse practitioners and other non-physician care providers should be expanded in a health reform environment to fill gaps in provider shortages. Dr. Hanson was extremely discouraged about the Affordable Care Act’s lack of focus on data and evidence-based medicine.
- **George Birdsong, MD:** Dr. Birdsong reported that the Grady Health System is in the final stage of fully implementing its electronic medical record system with a management reporting component in preparation of the Affordable Care Act. Grady will use these data to help guide and optimize care. Similar to other medical disciplines, pathologists also are attempting to become more efficient in a health reform environment. Pathology professional organizations are currently training and educating their members on strategies to educate clinicians on optimal laboratory testing protocols. The train-the-trainer approach is expected to produce more rapid and accurate work-ups and decrease the number of tests ordered to achieve cost-savings.
- **Chandana Nandi, MS:** Ms. Nandi is retired and serves as a part-time consultant to the National Latino Tobacco Control Network. She reported that the *2010 Surgeon General’s Report on Tobacco* listed tobacco as a contributor to both cervical and breast cancers. In terms of NBCCEDP’s future role in the context of the Affordable Care Act, she advised CDC to increase its focus on prevention education. Most clinicians who provide direct care to patients are unaware of the availability of CDC’s telephone tobacco quitlines. Ms. Nandi strongly encouraged CDC to develop an automated reminder system in which clinicians would be prompted to refer their patients who smoke to the tobacco quitlines. Because smoking is the number one preventable cause of death, automated referrals to the tobacco quitlines would be a valuable asset to health reform.
- **Gale Johnson, MPA:** Ms. Johnson reported that the Wisconsin Department of Health and Family Services will expand its reach to provide services to NBCCEDP-ineligible women in a health reform environment. Wisconsin is continuing to make presentations across the state to educate LCAs on this new approach. The FQHC network in Wisconsin that provides breast and cervical cancer screening is currently breaking

ground on two additional sites. LCAs have expressed concern about the potential impact of the Affordable Care Act on screening and treatment services for undocumented women. The Wisconsin BCC Program also is concerned about its uncertain future when the Affordable Care Act is implemented in 2014 and health outcomes for women who will be unable to afford health insurance under the Affordable Care Act.

- **Stephen Taplin, MD, MPH:** Dr. Taplin reported that NCI is a research agency and bases its funding, activities and decisions on solid evidence. Data show that the traditional system of reimbursement rather than care has been tremendously ineffective from a global health perspective. Of all developed countries, the United States ranks 16<sup>th</sup> in reducing avoidable causes of mortality and 19<sup>th</sup> in decreasing infant mortality. The country is well positioned to address the challenge of establishing a strong evidence and research base in a health reform environment. The new NCI Process of Care Research Branch is providing leadership in this effort by conducting research and generating evidence to respond to significant contextual changes and other problems in processes of care as a result of the Affordable Care Act. NCI's research with a cohort of 7 health maintenance organizations (HMOs) showed that 50% of patients with late-stage breast cancer and invasive cervical cancer had access to care for at least three years. NBCCEDP serves as an excellent model of the important role of evidence in influencing policies and practices. Lessons learned from NBCCEDP over the past 20 years can help prepare the country for health reform. Most notably, a large population of immigrants in the United States who receive care through NBCCEDP will have poor outcomes with the Affordable Care Act. NCI is funding a \$75 million research program to develop a national infrastructure for breast, cervical and colon cancers across the entire spectrum from screening to treatment. Research organizations will be funded to measure the size of the target population and the percentage of persons being screened, tracked and referred to treatment. NCI will use the infrastructure and evidence generated by the new research program to answer questions that will arise after the Affordable Care Act is implemented.
- **Nancy Lee, MD:** Dr. Lee reported that the HHS Office on Women's Health (OWH) is promoting its role as the primary source for women's health issues under the Affordable Care Act. Similar to CMS, HHS/OWH also is raising public awareness of the Affordable Care Act Pre-Existing Condition Insurance Plan. HHS set aside \$300 million for this initiative, but only \$20 million of the investment has been used to date. HHS/OWH will be extensively involved in the rollout of the IOM report on *Women's Health Preventive Guidelines*.
- **Yvonne Green, RN, CNM, MSN:** Ms. Green reported that CDC/OWH is focusing on its direct role in 3 of ~20 Affordable Care Act provisions specifically targeted to women's health. CDC/OWH's responsibilities under the Affordable Care Act are to: (1) address young women with breast cancer; (2) update the Pregnancy Risk Assessment Monitoring System questionnaire with a new question on the relationship between oral health and pregnancy; and (3) partner with other OWHs in HHS to serve in an overarching and coordinating role for outreach and education. CDC/OWH is currently tracking the roles, responsibilities and outcomes of the Affordable Care Act provisions that are specifically targeted to women's health. For example, CDC used Affordable

Care Act funding to establish a new Advisory Committee on Breast Cancer in Young Women. CDC/OWH recognizes that the magnitude and complexity of the Affordable Care Act have caused uncertainty and confusion across the government and in the general public. For example, the Affordable Care Act might require staff in CDC and other federal agencies to develop new skills set, expertise and leadership. CDC and its federal partners need to develop simple and consistent messages to clearly explain the impact of the Affordable Care Act to the public.

2. *What benefits can CDC offer to strategic public health efforts in implementation of the Affordable Care Act? What are the unique contributions of NBCCEDP in informing the Affordable Care Act? What NBCCEDP components can CDC use to take a proactive approach to inform changes as a result of the Affordable Care Act (e.g., share surveillance information and quality assurance measures with CDC leadership or policymakers)?*
  - Experts in other countries have strongly recommended over the past 15 years against conducting cancer screening outside of an organized screening program, but the United States has not adopted this approach to date. In a health reform environment, CDC should clearly explain and demonstrate the importance and value of NBCCEDP's unique role and infrastructure at the national level in collecting data, tracking populations, and linking quality standards or targets to funding to motivate BCC Programs to improve care. Most notably, NBCCEDP is the largest clinical surveillance system and the largest organized screening program in the country.
  - CDC should widely promote two additional unique aspects of NBCCEDP. First, NBCCEDP data have been used to publish data and formulate insights that have resulted in improved care. For example, the George Sawaya paper used NBCCEDP data to present a convincing and compelling argument that led to the American Congress of Obstetricians and Gynecologists adjusting its cervical cancer screening guidelines. The Rebecca Smith-Bindman paper used NBCCEDP data to compare breast cancer screening outcomes in the United States and United Kingdom. Second, NBCCEDP has a strong linkage to the Well-Integrated Screening and Evaluation for Women Across the Nation (WISEWOMAN) Program. WISEWOMAN provides low-income, under-insured and uninsured women 40-64 years of age with chronic disease risk factor screening, lifestyle interventions and referral services in an effort to prevent cardiovascular disease.
  - CDC should collect and review NBCCEDP data to determine the effectiveness of the reach of BCC Programs to their target populations; explore strategies to improve outcomes in communities; and identify potential implications of NBCCEDP quality measures on the Affordable Care Act. Data from this analysis should be packaged with terminology that will resonate with and be clearly understood by implementers of the Affordable Care Act. Most notably, CDC should present these data as a unique opportunity and resource to improve care in the United States with Meaningful Use incentives and interoperable data systems.
  - CDC should position NBCCEDP as a resource to assist persons who will be covered under the Affordable Care Act in navigating the system.

- CDC should compile data to demonstrate NBCCEDP's major benefit to all populations. Most notably, NBCCEDP has the capacity to improve the overall function of the healthcare system beyond breast and cervical cancer screening.
- CDC should explore opportunities to partner with ACOs to emphasize the strong role of NBCCEDP's outreach and education components. After the Affordable Care Act is implemented, ACOs will be required to meet the same performance measures (e.g., the percentage of patients in a healthcare system who received timely screening). CDC should obtain support and endorsement from ACOs for NBCCEDP's existing outreach and education activities.
- CDC should collect data to show differences in health outcomes of women before and after the treatment referral component was added to NBCCEDP. Although the Affordable Care Act will cover breast and cervical cancer screening without a co-pay, a large proportion of women with positive or abnormal screening results will be unable to afford co-pays for treatment and patient management care to navigate a complex and fragmented system.
- CDC should use NBCCEDP data to justify a new evidence-based approach of prioritizing case management of existing breast cancer patients over outreach to new populations.

3. *What components of NBCCEDP should CDC phase-out in a health reform environment?*

- Professional education and development for BCC Program providers. However, the BCCAC members noted their lack of knowledge of CDC's return on its investment for this component of NBCCEDP.
- The amount of time BCC Program administrative staff spends on issues that are not related to direct care (e.g., navigating the system to obtain coverage for patients and make referrals for patients without coverage). However, the BCCAC members noted that this suggestion was made without data from CDC on the amount of time BCC Programs devote to non-care issues.
- Tremendous co-pays for treatment of women with positive or abnormal breast or cervical cancer screening results.

4. *What program components would be different if CDC designed and implemented NBCCEDP in 2011 rather than in 1990?*

- A larger Congressional appropriation to ensure that BCC Programs have adequate funding to serve all NBCCEDP-eligible women in communities.
- A more holistic approach to address other health issues of women (e.g., diabetes and other chronic diseases) who are enrolled in BCC Programs for breast and cervical cancer screening).
- A stronger linkage to primary care physicians.

5. *What actions should CDC take to ensure a seamless transition to Affordable Care Act (e.g., promoting specific activities and sharing information with Medicare/Medicaid agencies and FQHCs)?*

- CDC should identify the population in the denominator of care that is being served and determine the proportion of this population being screened by FQHCs. CDC should use these data to link the data systems of BCC Programs and FQHCs to determine the total proportion of the population that was and was not screened. Based on 2009 data, FQHCs performed >2 million Pap smears and ~345 mammograms. CDC also should use these data to encourage FQHCs to strengthen their partnerships with CDC-funded BCC Programs and enhance outreach to increase breast and cervical cancer screening. Because FQHCs are mandated to serve all persons regardless of their ability to pay, FQHCs could serve as a safety network to fill the screening gap for women who are ineligible for NBCCEDP services.
- CDC should utilize its project officers to assist BCC Programs in focusing on the top 2 or 3 performance measures or quality indicators that are most important to their target populations.
- CDC should publish a *Vital Signs* report with 3 or 4 of the most important messages about NBCCEDP (e.g., its unique aspects, contributions and opportunities in a health reform environment). The *Vital Signs* report and other communications should be widely disseminated to inform decision-makers about the value of NBCCEDP to the Affordable Care Act. CDC also should partner with academia to use NBCCEDP data to publish papers that can change policy and encourage professional societies to serve as advocates for NBCCEDP with Affordable Care Act decision-makers.
- CDC should develop and specifically target innovative strategies to states and localities with low screening rates.

## Update on the 2006-2007 NBCCEDP Economic Analysis and Evaluation

### Donatus Ekwueme, PhD

Senior Health Economist, Program Services Branch, DCPC, NCCDPHP  
Centers for Disease Control and Prevention

Dr. Ekwueme presented an update on CDC's ongoing economic analysis and evaluation of NBCCEDP. CDC established six objectives for the study. A comprehensive analysis and evaluation of NBCCEDP would be conducted. The cost, effectiveness and cost-effectiveness of NBCCEDP would be estimated. Factors contributing to variations in costs per woman screened or served across funded BCC Programs would be identified.

The relationship between service delivery structures and the number of women screened or served would be determined. A threshold and scenario analysis would be conducted to determine the amount of women required to screen 25%, 50% or 75% of NBCCEDP-eligible women. Methods would be developed to inform the NBCCEDP budget and allocation of resources.

CDC developed the following methodology to perform the economic analysis and evaluation. Surveys were initially administered to 9 BCC Programs. A web-based cost assessment tool (CAT) was developed. Training materials were created and distributed to the participating grantees. Data were collected from the grantees in three rounds. Round 1 included 2006-2007 data; round 2 included 2008-2009 data; and round 3 included 2009-2010 data. After CDC reviewed and analyzed the data to assure quality, feedback was provided to the grantees.

CDC collected cost data at the activity level for the following NBCCEDP components and activities: program management, screening and diagnostic services, patient support and case management, quality assurance and improvement, partnerships, public education, professional development, data management, recruitment, evaluation, administration and other activities.

Dr. Ekwueme highlighted preliminary results of the round 1 data analysis. Estimates were generated of the total, mean and median number of women served by NBCCEDP from 2006-2007. A combination of federal, non-federal and in-kind funds used by 47 BCC Programs showed a total of 487,371 women served, a mean of 10,370 women served by each BCC Program, and a median of 6,561 women served across all BCC Programs. Federal funds alone used by 63 BCC Programs showed a total of 723,247 women served, a mean of 11,480 women served by each BCC Program, and a median of 9,209 women served across all BCC Programs.

Estimates were generated of the total, mean and median BCC Program costs from 2006-2007. A combination of federal, non-federal and in-kind funds used by 47 BCC Programs showed a total program cost of \$192.8 million, a mean total program cost of \$4.1 million, and a median program cost of \$2.9 million. Federal funds alone used by 63 BCC Programs showed a total program cost of \$255.8 million, a mean total program cost of \$4.1 million, and a median program cost of \$2.5 million.

Estimates were generated of the mean program costs per woman served from 2006-2007. A combination of federal, non-federal and in-kind funds used by 47 BCC Programs showed a weighted mean cost per woman served of \$395.59 and a weighted mean cost per woman served of \$92.34 from in-kind contributions. Federal funds alone used by 63 BCC Programs showed a weighted mean cost per woman served of \$353.65 and a weighted mean cost per woman served of \$204.15 for clinical services.

Estimates were generated of the mean number of women who were screened and had follow-up visits for abnormal results from 2006-2007. Of 63 BCC Programs that provided breast cancer screening, a mean of 4,509 women were screened with federal funds, 7,894 women were screened with both federal and non-federal funds, and 1,965 women received diagnostic follow-up visits for abnormal results.

Of 63 BCC Programs that provided cervical cancer screening, a mean of 4,858 women were screened with federal funds, 6,402 women were screened with both federal and non-federal funds, and 495 women received diagnostic follow-up visits for abnormal results.

Estimates were generated of the mean and weighted mean costs from 2006-2007. Of 63 programs that provided breast cancer screening, the mean costs were \$855,689 for the total cost of screening with an office visit and \$795,312 for the total cost of diagnostic procedures with an office visit. The weighted mean costs were \$108.46 per woman screened with an office visit (62 BCC Programs), \$404.79 for diagnostic procedures with an office visit (63 BCC Programs), and \$66.62 for mammography screening without an office visit (31 BCC Programs).

Of 63 programs that provided cervical cancer screening, the mean costs were \$375,956 for the total cost of screening with an office visit and \$208,964 for the total cost of diagnostic procedures with an office visit. The weighted mean costs were \$59.05 per woman screened with an office visit (62 BCC Programs), \$422.03 for diagnostic procedures with an office visit (63 BCC Programs), and \$20.20 for Pap smear testing without an office visit (36 BCC Programs).

Estimates were generated of the weighted mean cost per cancer detected from 2006-2007. Of 60 BCC programs that detected 5,801 breast cancers, all 60 detected 1,722 carcinoma *in situ* cancers and 58 detected 4,079 invasive cancers. The weighted mean costs per case detected were \$37,170 for all breast cancers, \$125,218 for carcinoma *in situ* cancers, and \$52,588 for invasive cancers.

Of 62 BCC programs that detected 5,284 cervical cancers, 16 detected 971 carcinoma *in situ* cancers, 61 detected 4,050 high-grade squamous intraepithelial lesions (HSILs), and 52 detected 263 invasive cancers. The weighted mean costs per case detected were \$15,850 for all cervical cancers, \$30,967 for carcinoma *in situ* cancers, \$20,663 for HSILs, and \$299,631 for invasive cancers.

Estimates were generated of the distribution of resources to each NBCCEDP component by percentage: screening and diagnostic services (~53%), patient support and case management (11.6%), program management (~9.6%), administration (~6%), data management (5.5%), recruitment (3.71%), public education (3.33%), professional development (2.01%), quality assurance and improvement (~2%), partnerships (~1.5%), other activities (1.05%), and evaluation (0.88%).

Estimates were generated of the mean costs per woman served by program component: \$203.58 for screening and diagnostic services (63 BCC Programs), \$38.63 for patient support and case management (62 BCC Programs), \$35.76 for program management (63 BCC Programs), \$17.95 for data management (61 BCC Programs), \$14.61 for administration (60 BCC Programs), \$12.77 for recruitment (48 BCC Programs), \$11.10 for public education (51 BCC Programs), \$8.75 for other activities (16 BCC Programs), \$7.70 for quality assurance and improvement (54 BCC Programs), \$7.05 for professional development (53 BCC Programs), \$4.50 for partnerships (47 BCC Programs), and \$3.69 for evaluation (46 BCC Programs). The economic analysis and evaluation showed that the total cost of serving each woman decreased as the total number of women increased.

Dr. Ekwueme summarized the preliminary round 1 results of the NBCCEDP economic analysis and evaluation. Overall, >95% of BCC Programs provided cost data at a level that was

acceptable for CDC to perform a detailed activity-based cost analysis. The three largest allocations of BCC Program resources were \$203.58 for screening and diagnostic services (or ~53%), \$38.53 for patient support and case management (or 11.6%), and \$35.76 for program management (or ~9.6%).

The costs per woman served were \$395.59 with a combination of federal, non-federal and in-kind funds and \$353.65 with federal funds only. The cost per woman served for clinical services was \$204.15. Estimated costs per woman screened by BCC Programs with an office visit were \$108.46 for breast cancer and \$59.05 for cervical cancer. Estimated costs of diagnostic procedures with an office visit were \$404.79 for breast cancer and \$422.03 for cervical cancer.

Estimated screening costs without an office visit were \$66.62 for mammography screening and \$20.20 for Pap smear testing. Estimated costs per cancer detected were \$37,170 for breast cancers and \$15,850 for cervical cancers. The economic analysis and evaluation showed that the cost per woman served tended to decrease as the number of women served by BCC Programs increased. This outcome reflects potential economies of scale in program operations.

CDC acknowledges several limitations with the NBCCEDP economic analysis and evaluation. The participating BCC Programs did not distinguish office visit costs by cancer sites. Office visit costs were proportionally allocated. The ability to separate costs incurred by each individual component was difficult due to the interrelationship between program components. As a result, the cost per woman served by some program components might be over- or underestimated.

Overall, significant variations were observed across the BCC Programs that participated in the economic analysis and evaluation. Estimated costs from the CAT-1 analysis per woman screened using mammography for breast cancer and Pap tests for cervical cancer are consistent with estimates reported in the literature. NBCCEDP appears to be cost-effective based on the preliminary economic analysis and evaluation results, but CDC needs to collect data from additional years before making conclusive statements.

CDC's next steps in the NBCCEDP economic analysis and evaluation will be to use two additional years of cost data that have already been collected to complete the study. CDC also will conduct an assessment of specific program factors that have the largest impact on variations in cost (e.g., a centralized, decentralized or mixed program design, geographic locations, and patient demographics of individual BCC Programs).

BCCAC noted that NBCCEDP costs increased over the three data collection cycles (e.g., 2006-2007, 2008-2009, and 2009-2010). However, these increased costs will be lower than the overall healthcare inflation cost. BCCAC advised CDC to compare the costs of the three data collection cycles to the overall healthcare inflation cost to demonstrate the added value of NBCCEDP.

Ms. Wong informed BCCAC that the Program Services Branch (PSB) Management Team would thoroughly review the preliminary results of the NBCCEDP economic analysis and evaluation to inform future decisions on funding allocations. PSB also would continue to review clinical cost

worksheets that all grantees are required to submit with their annual budgets. These worksheets provide the estimated number of women that grantees expect to screen for breast and cervical cancers in the upcoming year and Medicaid reimbursement rates in their states. PSB uses these worksheets to approve the proposed budgets of grantees.

With no further discussion or business brought before BCCAC, Dr. Ramirez recessed the meeting at 5:00 p.m. on June 16, 2011.

### **Opening Session: June 17, 2011**

Dr. Ramirez verified that the voting members and *ex-officio* members in attendance constituted a quorum for BCCAC to conduct its business on June 17, 2011. She reconvened the meeting at 9:00 a.m.

### **Overview of the George Washington University Modeling Study**

#### **Jacqueline Miller, MD, LCDR, FACS**

NBCCEDP Medical Director, DCPC  
Centers for Disease Control and Prevention

Dr. Miller provided BCCAC with the context of the George Washington University (GWU) Modeling Study. CDC recognized the need to address significant changes to NBCCEDP in the future as a result of the Affordable Care Act. One of CDC's key discussion topics was the need to determine persons who would remain uninsured and the proportion of uninsured persons who would continue to be eligible for NBCCEDP after the Affordable Care Act was implemented. CDC contracted GWU to conduct a modeling study to provide an assessment of this issue. GWU's first step in this effort was to conduct a legal analysis of the Affordable Care Act requirements and determine their applicability to NBCCEDP.

Dr. Miller informed BCCAC that the preliminary study results are expected to change and cannot be cited or distributed at this time. After the presentation, she would ask for BCCAC's input on potential strategies for CDC to use the modeling study data to inform NBCCEDP in the future. She also would ask BCCAC to provide recommendations or suggestions on additional analyses to refine the modeling study.

#### **Leighton Ku, PhD, MPH**

Professor of Health Policy, School of Public Health and Health Services  
Director, Center for Health Policy Research  
The George Washington University Medical Center

Dr. Ku highlighted key findings from GWU's legal analysis of the Affordable Care Act to inform the modeling study. The Affordable Care Act will substantially reduce the number of uninsured and low-income women and men. Beginning in January 2014, Medicaid eligibility will be increased to 138% of the FPL for adults. Health insurance exchanges will make private insurance more affordable and federal tax subsidies will have a threshold of up to 400% of the FPL.

A mandate will require individuals to have health insurance or pay a tax penalty, but exemptions will be available. Small business tax credits and other incentives will be given to employers to offer health insurance. Undocumented persons will not be eligible for health insurance under the Affordable Care Act. The Congressional Budget Office projects that the U.S. uninsured population will decrease by 32 million persons by 2019. However, ~24 million persons will continue to be uninsured in the United States.

In addition to reducing the number of uninsured persons, the Affordable Care Act also will change certain insurance mandates and coverage. Other than "non-grandfathered" plans, preventive services for Medicare and most private insurance will be required to be part of the benefit package. "Grandfathered" plans are private insurance policies that will not be significantly changed from the time the Affordable Care Act is implemented in 2014.

The required elements of preventive services include USPSTF A/B recommendations and HRSA-recommended services. The USPSTF guidelines include mammography screening for women 40-64 years of age, cervical cancer screening for sexually active women, and colorectal cancer screening for adults 50-64 years of age. The insurance plans will not require cost sharing if in-network providers offer preventive services. The insurance plans only apply to screening and will not include diagnostic tests.

For "traditional" Medicaid populations, preventive services will remain optional. If states offer preventive services without co-pays, federal matching dollars will be higher. However, any co-pays that are imposed will be nominal (e.g., <\$5.00). For "expanded" Medicaid populations (e.g., newly eligible adults who have no children and incomes 133% below the FPL and parents whose income eligibility levels will increase), preventive services will be required as part of the essential benefit package with no co-pays. Women who are screened by CDC-funded BCC Programs will continue to be eligible for Medicaid treatment under state options.

Dr. Ku presented an overview of GWU's approach and methodology to conduct the modeling study. CDC contracted GWU to determine changes in insurance coverage to estimate the number of women who would remain eligible for NBCCEDP by state. NBCCEDP eligibility depends on five major factors: gender (e.g., women); age (e.g., 40-64 years of age for breast cancer screening, 18-64 years of age for cervical cancer screening, and 50-64 years of age for colorectal cancer screening); state income criteria (e.g., a range of 200-250% below the FPL); priority populations (50-64 years of age for breast cancer screening and 40-64 years of age for cervical cancer screening) and insurance status (e.g., uninsured or under-insured).

For purposes of the modeling study, GWU focused on uninsured populations. The legal analysis of the Affordable Care Act showed that due to changes in insurance coverage and cost-sharing requirements, a minimal number of insured women will be under-insured for breast or cervical cancer screening. Moreover, GWU did not have sufficient information on approaches BCC Programs take to determine their under-insured populations.

GWU's conceptual approach to conducting the modeling study was to apply the experience of Massachusetts due to its implementation of a state health reform law in 2007. The state's uninsured rate dramatically decreased and now ranks as the lowest uninsured rate in the country.

To a great extent, federal health reform was modeled after state health reform in Massachusetts and its prior policies in insurance expansions (e.g., expanded Medicaid coverage, expanded private coverage with exchanges and subsidies, and the mandate for each individual to have health insurance or pay a tax penalty). GWU made adjustments to the Massachusetts experience to simulate outcomes of health reform to the remainder of the country.

GWU used the 2009 American Community Survey Public Use Microdata System (ACS-PUMS) due to its coverage of 3 million persons (or 1% of the U.S. population). The survey provides data on socioeconomic situations, race/ethnicity, employment, disability and health insurance coverage. GWU used multivariate regression models to determine insurance coverage in Massachusetts in 2009. Separate models were developed for males and females 18-64 years of age. The predictive model included >20 variables to predict health insurance coverage (e.g., age, employment, disability, citizenship status, race/ethnicity, educational status and marital status).

GWU used and applied coefficients from the Massachusetts model to specific characteristics of every individual in the ACS-PUMS sample. Adjustments were made for citizenship status in Massachusetts and other states that have more liberal policies for Medicaid eligibility of legal non-citizen immigrants. Adjustments were made for national benchmarks that report national uninsured rates of 9.5%-10% among adults by the time the Affordable Care Act is implemented. State "fixed effects" were used to determine residual amounts in states that differ from Massachusetts after controlling for all personal characteristics, policy differences and environmental differences. Adjustments were made for aging and growth of the population from 2009-2014.

Dr. Ku highlighted key preliminary findings from the modeling study. Based on current income criteria in each state, GWU estimated the following reductions in the number of NBCCEDP-eligible women from 2009-2014: a 62% reduction in breast cancer screening nationally for women 40-64 years of age with variations by state; a 60% reduction in cervical cancer screening nationally for women 18-64 years of age; and a 61% reduction in colorectal cancer screening nationally for women and men 50-64 years of age.

GWU estimated the following uninsured rates by state for low-income women 40-64 years of age at 250% below the FPL in 2014: <8% in the District of Columbia and 14 states, 8%-9.9% in

18 states, 10%-13% in 10 states, and >14% in 8 states. The national uninsured rate currently is 31% for low-income women 50-64 years of age at 250% below the FPL.

Based on current state income criteria, GWU estimated the following reductions in the number of women who would be eligible for NBCCEDP-funded breast cancer screening from 2009-2014: a <50% decline in 7 states and the District of Columbia; a 50%-65% decline in 15 states; a 65%-73% decline in 18 states; and a >73% decline in 10 states.

GWU described the characteristics of uninsured women 40-64 years of age with incomes below 250% of the FPL who would be eligible for NBCCEDP-funded breast cancer screening in 2009 and 2014. There are expected to be significant shifts in the racial/ethnic composition of the NBCCEDP-eligible population. Among women eligible for breast cancer screening, the percent who are Hispanic would increase from 27.6% in 2009 to 41.1% in 2014. Of African American women, the 16.3% in 2009 would decrease to 12% in 2014. Of white women, the 48.8% in 2009 would decrease to 38.9% in 2014. Of American Indian women, the 1.2% in 2009 would decrease to 0.8% in 2014. Of Asian women, the 4.5% in 2009 would increase to 6% in 2014.

When looking at immigrants, the percent of eligible women who are non-citizens would increase from 22.3% in 2009 to 38.9% in 2014. Of women with limited English proficiency, the proportion would increase from 26.4% in 2009 to 39.4% in 2014. The percent of non-citizen women and women with limited English proficiency who would be eligible for NBCCEDP-funded breast cancer screening will significantly vary across states.

GWU acknowledged the following limitations of the modeling study. The study was based on non-institutionalized populations and does not include persons in institutionalized settings (e.g., nursing homes and correctional facilities). All forecasts assume that history can be used to predict the future, but this traditional approach is not fully accurate.

Two key assumptions were made: 1) Income, employment and other factors in 2014 would be similar to those in 2009 and 2) The national health reform law would be implemented in a comparable fashion as the Massachusetts state health reform law. Also, the ACS-PUMS defined "incomes" on an annual basis, but BCC Programs may use current incomes instead of the prior 12 months since there are variations throughout the year.

Dr. Ku concluded his overview by reporting that GWU's next steps of the modeling study are to provide CDC with data on potential policy implications for NBCCEDP post-health reform in light of the estimated changes in the number of NBCCEDP-eligible women. GWU will engage in discussions with CDC and the ACS Cancer Action Network to launch this component of the study.

BCCAC commended CDC for contracting GWU to conduct the important modeling study to prepare for the future direction of NBCCEDP in a health reform environment. The BCCAC members made two key suggestions for CDC and GWU to consider in further implementation of the study.

GWU should design the modeling study to identify the number of women currently served by NBCCEDP and project the number of women outside of the Affordable Care Act who NBCCEDP could serve in the future. This approach could provide data on reductions in breast cancer morbidity and mortality and allow CDC to establish targets for hard-to-reach populations. CDC should monitor the NBCCEDP population to determine the accuracy of GWU's modeling results.

## Public Comment Session

### **Mary Dolan, MD, MPH**

Department of Gynecology and Obstetrics  
Emory University School of Medicine

Dr. Dolan shared the concerns the BCCAC members expressed over the course of the meeting regarding funding cuts to NBCCEDP, particularly since GWU's preliminary data showed that more women would be eligible for NBCCEDP when the Affordable Care Act is implemented in 2014. She also was concerned about efforts to shift the focus of NBCCEDP to older women because this approach would overlook the at-risk and underserved population of younger women.

## BCCAC Open Discussion: Session 2

Dr. Ramirez opened the floor for BCCAC's open discussion on the potential impact of the Affordable Care Act on NBCCEDP.

- 1. What are the populations that will remain uninsured and eligible for NBCCEDP-funded services after the Affordable Care Act is implemented? What strategies should CDC implement to further improve health care at a broader level (e.g., focus on disparities, the safety net, specific target populations and cancer screening surveillance)?*
  - USPSTF is currently revising its cervical cancer screening guidelines. The potential for raising the age recommendation to  $\geq 21$  years of age and changing the screening intervals is expected to have an impact on NBCCEDP.
  - CDC designed the NBCCEDP Promising Practices Assessment to exclude practices that have been rigorously evaluated or published in the literature. CDC should reconsider this approach because "proven" interventions in a particular population and setting or under a given set of circumstances will not necessarily translate to other settings.
  - CDC should analyze and publish promising practices for breast and cervical cancer and other preventive care practices for different subpopulations in diverse settings (e.g., African Americans, Hispanics and Asians)

- Organizations that will be awarded CDC-funded Community Transformation Grants will be required to offer training to providers on preventive services. DCPC should ensure that tobacco control is included in training activities to providers.
- CDC should explore opportunities to restructure NBCCEDP's existing infrastructure with a stronger focus on outreach and promotion of prevention beyond screening. CDC should take advantage of the recent announcement by the HHS Secretary on national efforts that will be made to shift prevention outside of medical homes.
- CDC should collaborate with its federal partners to increase outreach to lesbian women to encourage breast and cervical cancer screening. This population is frequently overlooked, extremely hard to reach, and typically does not present for preventive health services.
- CDC should place a much stronger focus on targeting preventive health services to women with limited English proficiency and non-citizen women by developing new materials, implementing innovative screening approaches in non-traditional venues, and using MDE data for modeling purposes. Most notably, preliminary results from the GWU modeling study showed that the percentage of women with limited English proficiency who would be eligible for NBCCEDP-funded breast cancer screening would increase from 26.4% in 2009 to 39.4% in 2014. The preliminary data also showed a substantial increase in the percentage of non-citizen women who would be eligible for NBCCEDP-funded breast cancer screening (e.g., from 22.3% in 2009 to 38.9% in 2014). Because the vast majority of non-citizen women will be from countries with no formal breast or cervical cancer screening programs, BCC Programs most likely will detect a greater number of abnormalities and late-stage disease at the first screening visit. CDC should design new outreach efforts to target different subgroups within broader racial/ethnic groups, particularly Asian and Hispanic populations.
- CDC should encourage BCC Programs to devote a portion of their 40% non-screening dollars to technology to increase screening rates. For example, the "Text4Baby" health education program delivers wellness and health text messages to mobile phones of expectant and new mothers. CDC should determine whether BCC Programs could use a portion of the Affordable Care Act's information technology funds to replicate this model for outreach and case management.
- The President's Cancer Panel recently published a demographics report on the shift in race/ethnicity and other factors and their impact on the U.S. cancer burden. CDC should use the projections and other data in the report as an initial step in modeling populations that will remain eligible for NBCCEDP after the Affordable Care Act is implemented in 2014.

Dr. Plescia and Ms. Wong provided comments in response to two of BCCAC's suggestions on question 1. First, CDC established a new policy in 2010 that requires all BCC Programs and their sub-awardees to screen for tobacco use during breast and cervical cancer screening and refer smokers to tobacco quitlines. Second, many BCC Programs specifically target and conduct outreach activities to the lesbian population. CDC has formed strong partnerships with national organizations that represent lesbians as well.

2. *What strategies should CDC consider to encourage other groups to engage in NBCCEDP's organized screening approach?*

- CDC should compile and widely publicize solid data to demonstrate NBCCEDP's success in screening and outreach, particularly in hard-to-reach populations. The data also should be used to compare NBCCEDP's outcomes of diagnostic testing and referrals to treatment to those of Medicare and other groups. Moreover, CDC should gather process data by comparing MDE data to tracking and quality improvement systems in an integrated HMO (e.g., Group Health or Kaiser) and fee-for-service data sets (e.g., Market Scan). To inform health policy, CDC should compare MDE data to the Healthcare Effectiveness Data and Information Set to determine differences in the time and proportion of persons with abnormal screening tests who receive follow-up. CDC should disseminate data from these comparative analyses to insurance plans and other groups that represent large groups of women to present a compelling case on the importance of organized screening.
- CDC should explore the possibility of serving in an advisory role to provide guidance and technical assistance on activities that BCC Programs conduct with their 40% non-screening dollars.
- The "Ask Me" Campaign implemented by the Seattle, Washington BCC Program should be reviewed as a potential model in identifying women in the field who have never been screened. In this campaign, community workers in grocery stores and a variety of other local settings inform low-income women of locations that offer mammograms at no charge. The campaign should be replicated at the national level as an organized approach to outreach hard-to-reach populations.
- CDC should encourage BCC Programs to collaborate with large health systems to access their data on uninsured women who are unable to pay for preventive care and present to healthcare facilities for urgent care.
- CDC should give careful consideration to identifying the NBCCEDP priority populations and ensuring that referrals can be made for these women to receive services. For the priority population of undocumented women who BCC Programs cannot legally serve, CDC will need to closely collaborate with advocacy organizations to make appropriate referrals. An additional priority population is insured women with positive or abnormal screening results who are unable to pay onerous co-pays to obtain diagnostic testing.

3. *What should be CDC's role during the Affordable Care Act enrollment process?*

- CDC should develop a training and education program to train BCC patient navigators on enrolling their clients into the Affordable Care Act.

4. *What should CDC monitor (e.g., capacity and access to care) to track effective and non-effective practices in cancer screening?*

- Access to care will increase in many states after more persons are insured under the Affordable Care Act. CDC should encourage BCC Programs to adopt a "tiered" approach to service delivery after the Affordable Care Act is implemented. For example,

nurse practitioners could provide care to patients in situations where a physician would not be necessary.

- CDC should collect data from state cancer registries to track rates of late-stage breast cancer and invasive cervical cancer. These rates are expected to increase because women with no breast or cervical cancer screening history will be screened for the first time under the Affordable Care Act. CDC also should make efforts to add NBCCEDP-specific questions to surveys that are used to populate state cancer registries.
- From a quantitative perspective, CDC should use sources other than BRFSS to monitor the rates of screening offered and the level of awareness and knowledge of screening in the NBCCEDP-eligible population. Poor response rates to BRFSS have made this data set questionable. CDC should determine whether BCC Programs could use a portion of their 40% non-screening dollars for this effort. From a qualitative perspective, CDC should greatly increase their conversations with Program Directors and providers in BCC Programs to obtain input on any new changes in NBCCEDP. CDC should contract an organization to convene focus groups and hold bimonthly conference calls to engage Program Directors and providers in dialogue on a regular basis.
- To track effective and non-effective cancer screening practices, CDC should establish an electronic data monitoring system that would automatically collect data from electronic health records.
- Because disease is predicted by age, race and other factors, CDC should generate estimates of demographic differences in the NBCCEDP-eligible population when the Affordable Care Act is implemented in 2014 to inform the development of future strategies. On the one hand, more emphasis should be placed on patient navigation, diagnostic treatment and referrals to treatment if the burden of disease is substantial among women with health coverage who are enrolled in BCC Programs. On the other hand, more emphasis should be placed on outreach if the burden of disease is disproportionate among women outside of BCC Programs without health coverage.

### **Demonstration of the NBCCEDP 20<sup>th</sup> Anniversary Toolkit and Video**

#### **Jacqueline Miller, MD, LCDR, FACS**

NBCCEDP Medical Director, DCPC  
Centers for Disease Control and Prevention

Dr. Miller reminded BCCAC that during the March 2010 meeting, CDC presented an overview of activities that would be conducted to celebrate the 20<sup>th</sup> anniversary of NBCCEDP. During the celebration, CDC presented a video to illustrate NBCCEDP's rich history, several Program Directors presented a play, ballet dancers performed a dance, and a choir sang songs.

CDC also collaborated with partners and NBCCEDP grantees to develop a toolkit to strengthen capacity in improving partnerships and outreaching to non-traditional groups. The toolkit includes a standardized set of resources, but the materials can be tailored to meet the specific needs of each individual grantee. Dr. Miller summarized the key features of the toolkit.

The introductory letter by Ms. Faye Wong, Chief of PSB, describes the components of the toolkit, highlights resources that are available to grantees, and provides guidance to grantees on areas to develop or enhance in the future. The media relations component of the toolkit clearly defines “public relations” and provides guidance to grantees on successfully reaching the public.

Sample messages or “talking points” are provided to increase the effectiveness of grantees in making a full presentation or briefly highlighting key topics to engage new partners, particularly those outside of public health. Strategies are outlined for grantees to collaborate with different types of partners (e.g., local governments, corporations, national organizations, or community-/faith-based organizations). A sample “pitch” letter is included for grantees to send to potential new partners.

The toolkit also includes a wealth of other resources (e.g., answers to frequently asked questions, breast and cervical cancer fact sheets, templates for grantees to describe state, local or community activities of their individual BCC Programs, and templates for grantees to formally recognize the contributions of their partners). Dr. Miller presented the NBCCEDP 20<sup>th</sup> anniversary video in which two cancer survivors and partners of BCC Programs shared their personal experiences. She pointed out that the video of the celebration activities and the toolkit were distributed to BCCAC for review.

BCCAC applauded CDC on developing an inspirational and powerful video to showcase the 20<sup>th</sup> anniversary of NBCCEDP. BCCAC also congratulated CDC on its outstanding accomplishment of conducting NBCCEDP over the past 20 years. When the current five-year reauthorization cycle ends in 2012 or thereafter, the BCCAC members strongly advised CDC to compile solid data and extensively engage partners to inform this effort.

## Closing Session

The terms of Drs. Amelie Ramirez, George Birdsong and Carl D’Orsi ended in March 2011. The participants applauded the outgoing BCCAC Chair and members for their commitment to and participation on BCCAC over the past 4 years. Dr. Ramirez was particularly recognized for her outstanding leadership in planning and managing BCCAC meetings. Drs. Ramirez, Birdsong and D’Orsi (*in absentia*) were presented with certificates of appreciation for providing CDC with valuable advice and recommendations on NBCCEDP during their tenure.

The participants joined Dr. Ramirez in applauding the BCCAC members for providing excellent guidance and thoughtful insights to CDC on the complex issue of the future role of NBCCEDP in a health reform environment.

With no further discussion or business brought before BCCAC, Dr. Ramirez adjourned the meeting at 12:00 p.m. on June 17, 2011.

I hereby certify that to the best of my knowledge, the foregoing Minutes of the proceedings are accurate and complete.

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Date

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Amelie G. Ramirez, Dr.P.H., M.P.H.  
Chair, Breast and Cervical Cancer Early  
Detection and Control Advisory Committee