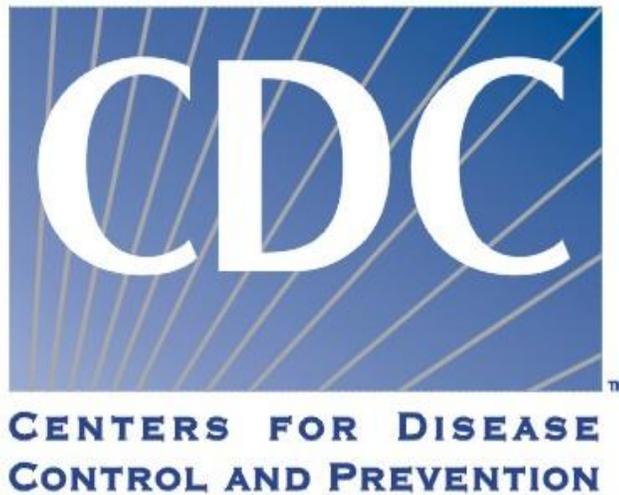


**BREAST AND CERVICAL CANCER EARLY DETECTION AND CONTROL  
ADVISORY COMMITTEE MEETING**



**December 6-7, 2012  
Atlanta, Georgia**

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**Record of the Proceedings**

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**BREAST AND CERVICAL CANCER EARLY DETECTION AND CONTROL  
ADVISORY COMMITTEE MEETING  
CENTERS FOR DISEASE CONTROL AND PREVENTION  
University Office Park Campus  
Columbia Building  
Atlanta, Georgia  
December 6-7, 2012**

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**THURSDAY, DECEMBER 6, 2012**

**OPENING AND WELCOMING**

**Jameka Blackmon, Designated Federal Officer (DFO)**

Ms. Blackmon welcomed members to the meetings and to Atlanta. She also went around the room and introduced key staff members who were instrumental with meeting logistics. Roll was taken to ensure quorum. The following board members were present either in-person or by phone:

- Dr. Jewel Mullen, Chair
- Ms. Jameka Blackmon, DFO
- Dr. Phillip Castle
- Ms. Pamela Wilcox
- Dr. Mary Dolan
- Dr. Jean Ford
- Dr. Paula Lantz
- Ms. Melissa Leypoldt
- Dr. Marina Mosunjac
- Dr. Evan Myers
- Ms. Chandana Nandi
- Dr. Catherine Oliveros
- Dr. Handel Reynolds
- Ms. Yvonne Green
- Dr. Nancy Lee
- Dr. Stephen Taplin
- Dr. Sabrina Matoff-Stepp
- Dr Richard Wild

Only the Chair, Members, and Ex Officio Members were allowed to participate in the discussions. The public was asked to reserve any comments until the public discussion portion on the agenda. No conflicts of interest were identified by the members, but they were asked that if conflicts of interest were identified during the meeting to please notify Dr. Mullen or Ms. Blackmon.

Dr. Jewel Mullen, who is the new chair of the committee, was given a formal introduction by Ms. Blackmon. Dr. Mullen stated she was honored to sit on the board and that she believes the committee will bring a lot to the discussion to help CDC ensure that services provided by the program have a place in the evolving health care landscape.

Each of the members also introduced themselves. Because so many of the committee members are new to the board, a brief overview of the roles and responsibilities of the

advisory committee was provided by Ms. DeAndrea Gardner, CDC's Management Analysis and Services Office representative.

**DIVISION OF CANCER PREVENTION AND CONTROL UPDATE**  
**Dr. Marcus Plescia, Director, Division of Cancer Prevention and Control (DCPC),**  
**CDC**

Dr. Plescia welcomed the committee members to Atlanta and thanked them for participating on the committee. There are a number of new members joining the board this year, which bring diversity in input to the program. He acknowledged his excitement at seeing Dr. Mullen appointed as the new chair and expressed that her background would be a great asset to the board. He noted he was anxious to hear the committee's feedback.

Dr. Plescia also noted there is a little more certainty of where things are going. The last time the committee met there was question of what would happen to the Affordable Care Act (ACA), but it is now going forward. Some things are still uncertain due to possible sequestration by Congress right now. There isn't a formal 2013 budget, so CDC has gotten permission to spend according to its last budget. The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is putting forward a proposal for reauthorization and will be briefing the members on what will be put forward for that reauthorization and what opportunities the program thinks are available there. The cancer programs at CDC have done a good job of proactive planning despite uncertainties, and CDC has a pretty good idea of how these programs will play out in the future.

A two-page document called Moving Forward was created, which talks about the potential future roles for public health and its role in screening. It also talks about projects that have been completed that will help position the NBCCEDP for the future. Some of the projects will be talked about during the meeting and Dr. Plescia is eager to hear the group's feedback and thoughts about them.

CDC presented the work of Dr. Leighton Ku and what the ACA means for those who have insurance and those who don't. That work was presented last year and will be talked more about later.

CDC also re-competed all of its cancer program grants, except colorectal, and has asked states to put forward ideas on ways to work collaboratively with health departments to bring about systems change that result in stronger delivery in cancer screening services. The program received fantastic responses and got just short of 20 proposals, but was only able to fund 2, which was a little disappointing. This shows that there is capacity for states to interface with health systems.

Two projects were funded at \$1 million a year each. One of the projects is in New York State, who is working to provide more organized care around diabetes and

cardiovascular disease. This funding will allow them to expand their efforts to include cancer screening. In addition, they are making advances in electronic health records (EHR) and will be able to look at ways to monitor cancer screenings using the EHR. The other project in Minnesota is looking at ways they can be more aggressive with cancer screening among their Medicaid population.

There is also a smaller project across some states looking at similar Medicaid collaborations. This project has been working with Michigan and North Carolina to work more robustly with their Medicaid programs and will also be offering this opportunity to a few more states.

The presentations for this meeting are designed to provide more information to the committee. Dr. Plescia believes that the expertise possessed by the committee will help the NBCCEDP staff in their planning.

The majority of the meeting, both day one and day two, is designed to stimulate thoughts among committee members by using a discussion format with a few presentations in between to provide information and insight. The following is the discussion that took place after Dr. Plescia's presentation.

J. Ford: Is it possible to think of a strategy that's extended to safety net hospitals?

M. Plescia: That is a good idea. The idea of doing small grants could foster relationships.

J. Mullen: Given the uncertainty and thinking about the thought of bringing the pathologist "out of the basement," as we're thinking about the comprehensive system, is there anything else you would say to help guide us in our thinking?

M. Plescia: One of the arguments we've tried to make is we need a more organized approach particularly with clinical services. And we need to do that in a population-based way. One of the things that we're very proud of is our tracking system. We do have strong accountability. If states don't meet required benchmarks, we can cut their funding. So there are some sticks and carrots out there. That's another piece of having an organized approach. Public health and health departments can be catalysts in helping to continue this organized approach and make it well-orchestrated.

N. Lee: In Europe, they say there should be no cancer screening unless it's in an organized fashion. This program is the only organized cancer screening in the United States. So I agree that as we move forward a bigger role is to get this population-based so that everyone is tracked. It's uniform, and we can expand it to others.

- S. Taplin: The challenge we've always faced is budget. Is there going to be any change in the Affordable Care Act that change how you use incentives to find those individuals that are not normally reached?
- M. Plescia: Yes, there are some women who will need subsidized services and still won't have insurance. Our hope is we move to a place where we can reach a large enough proportion of women, and we have to do some outreach to get to those women, who are not normally reached. I think there are some opportunities there.
- P. Castle: I think outreach is important and the issues are more than monetary but are also about engagement. We have to knock on the doors to get to some of those small groups. We also have to make sure we're marketing the vaccine for HPV to counteract cervical cancer. We can see a huge cost savings by preventing even a small group of cases there.
- M. Plescia: The challenge for breast and cervical cancer is we have to make a really compelling case that the problems are solved because the Affordable Care Act and preventable services are available.
- J. Mullen: So we need to define the problem, so people can't just say the problem is solved.
- P. Lantz: Is there anything you can share about the Massachusetts mandate and how it played out in that state?
- M. Plescia: That was looked at by George Washington University. Massachusetts put emphasis on patient navigation and participated in the waivers that we offered to get out of the 60/40 rule. This allowed them to experiment and try different things. We are still gleaning some information but that is a good case study to look at what was done that other states could follow.
- S. Taplin: So problem solved in Massachusetts? Is it or is it not?
- J. Mullen: We're defining the problem. The problem is not solved. The system is not just flawed but trying to improve. There's a small denominator, and we don't even know everybody in it. So that's a problem. We have disparities. That's a problem. We have uncounted populations. We have a national program that has to get implemented at a state level. So we can say we addressed some problems, but now let's see what else we can take on. There are some people that will have insurance, but their deductibles will be too high. That's an issue. Having worked in Massachusetts, there

were still many problems to work with. We still felt like we weren't improving the health of the whole person because of the many problems using the system that have been left unresolved. It's not just about insurance.

M. Plescia: We can learn a lot from Massachusetts but it's an exceptional state, so it was hard to see a difference. They already had pretty robust programs.

N. Lee: It's not Texas.

M. Plescia: Exactly. And Texas is probably one of the states saying it's not going to do Medicaid expansion. So if there are still challenges in Massachusetts, you know in other states, there are humongous challenges. So that's our argument for more flexibility.

M. Leyboldt: And even the databases you have aren't always relevant. The populations change so quickly so that's another reason why you need to stay flexible.

S. Taplin: Can you clarify the application process?

M. Plescia: We're pushing in the grant application for a population-based approach and particularly to underserved populations. We can't move totally away from the screening piece, but we also want programs to look at public health approaches around screening. We're looking at outreach and how they work with the healthcare system.

J. Mullen: Do you think the problem is the same as the one last time we met?

N. Lee: There are many problems, and maybe we can identify three or four problems to take on. It is a moving target. I met with our person who works with the Affordable Care Act, and they are flying the plane as they are building it. They don't want to build consumer messaging until they have the content, so there will be some challenges.

M. Plescia: We need to give a strong message of what we address that resonates with Congress.

P. Castle: You can say that in outreach we'll reach X number of women to be screen for cervical cancer. This is a business decision, and this is return on investment.

- S. Matoff-Stepp: Maybe this is an opportune time to do a subgroup or subcommittee to focus or have focused talks. Women's health is a high priority right now in this administration. We have an opportunity now and we need to act on it, and we may not have it again. I say that broadly we don't have to limit it just to breast and cervical.
- S. Taplin: The message isn't complicated. Reduce the rate of late stage breast and cervical cancer for everybody. I think there is a way to say it fairly succinctly.
- P. Lantz: Screening isn't the endpoint because it doesn't do any good to do screening if they don't get into appropriate, high-quality treatment. So we need to go further than just screening.
- J. Ford: One of the realities that we face is we know where people are and we should impact specific populations using geographic information systems that can inform where to target interventions.

#### **OVERVIEW OF THE NATIONAL BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAM**

Program staff engaged in a panel discussion to give committee members more insight into the Breast and Cervical Cancer Program. The discussion was moderated by Ms. George-Ann Townsend. Panel members included Mr. Jerry Cook, Ms. Felicia Solomon, Ms. Janet Royalty, and Ms. Quanza Brooks-Griffin.

Below is the discussion of that panel.

- G. Townsend: Tell us how the program got started.
- J. Cook: Congress enacted the Breast and Cervical Cancer Mortality Act in 1990, which directed CDC to start a breast and cervical cancer screening program. There are some advantages and disadvantages to having a statute. It's been described as being prescriptive and requires the eight components of which include screening, tracking, follow-up, data, surveillance, evaluation, and case management, just to name a few. There's also the 60/40 requirement, which mean at least 60% of funds will be used for screening and case management and not more than 40% will be used for everything else. When Congress reauthorized the law, in 2007, they offered a one-time waiver of the 60/40. But this is how we got going. Congress then also identified a need to provide for cancer treatment; and now the Medicaid Treatment Act is now available in states.
- G. Townsend: Is it for all women?

- J. Cook: It is for low-income women. None of this money can be used for research. It's a women's screening program.'
- G. Townsend: How many programs have been funded?
- J. Cook: The program funds 67 states, tribes and territories.
- G. Townsend: We'll now talk about the women that come into the program. Do they get free mammograms and Pap tests Felicia?
- F. Solomon: We have a required component called targeted outreach, which builds up demand for screening services. It informs women that these services are available, the importance of screening and follow-up, where services are available, etc. Also, public education. We're educating all women, those eligible and ineligible, to know about screening.
- G. Townsend: How do women find out about the program?
- F. Solomon: States do targeted outreach by using surveillance data to find their populations. They might do any number of outreach depending on what their data says. They might do partnering to do group targeted education, public services announcements, etc. They might also do in-reach with women who are already enrolled in health centers.
- G. Townsend: Janet, how many women do you have in this program?
- J. Royalty: We screen about 500,000 women each year, and we've seen over 4 million women. We collected a record on all these women, which provide us with datasets, called MDEs (Minimal Data Elements). Each record tracks the woman through diagnostic follow-up, even if her care is transferred to an outside agency.
- G. Townsend: So this is like a data collection system?
- J. Royalty: Our data allow us to give feedback to our programs and help us to set our priority indicators. Our grantees have developed the same measures that they provide back to their provider networks. It informs them on whether they're accomplishing their goals.
- G. Townsend: Can you tell us about professional development in the program?
- Q. Brooks-Griffin: We have a program called QSST (Quality Services Support Team) that works with our data management and evaluation team to

monitor, assess, and improve outcomes. There are three components of QSST: professional development, quality improvement, and case management.

G. Townsend: You have QSST and professional development components. What do physicians do in these components?

Q. Brooks-Griffin: If patients are not coming back in for follow-up, they work with programs to identify where the gaps are and the issues. They may employ flowcharts to improve their processes. They may do provider assessments or talk with employees to see where there are issues.

G. Townsend: I want to thank all of my panelists, and I hope this overview is productive and helps you understand some components of the program.

#### **QUESTION & ANSWER**

S. Taplin: You said there were 500,000 women screened. How many breast and how many cervical?

J. Royalty: About 300,000 breast and the remaining cervical.

S. Taplin: Is the data public?

J. Royalty: We do not have public data, but we do have data sharing agreements with external and internal investigators.

Y. Green: In the last five years with a lot of economic turmoil, how have you all had to adjust the program particularly for states with severe fiscal problems?

J. Cook: The program is for all eligible women, but we also try to focus on the age group where we'll have the most effect, 50-54 year olds for breast screening and 40-64 year olds for cervical. Unfortunately, federal funds haven't fluctuated a lot, and states really do depend on the federal funds.

G. Townsend: Many state programs are depending on CDC solely for those funds for screening.

J. Cook: The law requires a match of \$1 of non-federal for every \$3 of federal funds, and it can be in a variety of forms. We reimburse for clinical services at the Medicare reimbursement rate.

- P. Castle: Now that we have national guidelines and agreements on co-testing, is there any move to use that? Maybe we want to offer them the best single-time screen in case they won't come back for follow-up.
- J. Miller: We do pay for co-testing so every client can get HPV with their Paps. We can do that to alleviate some follow-up issues. When we speak about quality, we're talking about timely services. We don't monitor the quality of the procedure itself, but that you're getting the services, and that certified labs are doing the testing.
- P. Castle: How do you know that the labs are providing the best quality?
- J. Miller: We rely on that piece from the states to make sure that the labs are quality labs.
- M. Dolan: Guidelines might change. How quickly can guidelines be adapted into the program?
- J. Cook: We have a provision in the law that things have to be scientifically based before they can be put into use.
- J. Miller: The program does not make screening guidelines. We have recommendations of what we will reimburse for.
- S. Taplin: What's the rationale for cutting off after 65 [years old]?
- M. Dolan: Do you have problems that you want us to consider?
- J. Royalty: Our focus is on direction and priorities that will move us forward.
- G. Townsend: And who are we going to be targeting. It has always been women who have rarely or never been screened. This will require us to regroup and reflect on our successes. It used to be women who were underinsured or uninsured, but now that they will have insurance, we have to rethink that.
- Q. Brooks-Griffin: Also consider programs in the Pacific Islands who are working with substandard equipment. Often times their mammography machines do not work well, if at all.
- J. Cook: We have many different programs, and we're challenged in helping them with their varying needs. I don't know how much help you can be on that, but that is an area where we also need assistance.

**PRESENTATION: WHAT CDC IS CURRENTLY DOING**  
**Ms. Faye Wong, Chief, Program Services Branch, DCPC, CDC**

The Affordable Care Act is a real opportunity for public health and cancer screening because it increases access to cancer screening for millions. The Act requires coverage of USPSTF recommended preventive health services, grades A and B, with including breast, cervical and colorectal cancer screening and eliminates cost-sharing. The Act has requirements for new health insurance plans, state insurance exchanges, Medicare, and the new Medicaid Expansion.

Several needs and opportunities have been identified. Screening rates are not optimal, and there is room for improvement. The national screening infrastructure has to be designed to meet the need of unique populations, such as rural, tribal, and urban areas. There are evidence-based interventions that are effective in increasing cancer screenings. The desire is to take the infrastructure expertise and expand it on a population-level to increase population-level screening. The program is looking to the Advisory Committee for ideas on direction and ways to achieve population-level outcomes. It's about action and creating what cannot be seen. It's about connection and connecting to partners and systems. It's about deviation and forging new paths.

The Breast and Cervical Cancer Program started in 1990. In 2009, CDC received funding to start the Colorectal Cancer Control Program and received \$25 million compared to the \$180-190 million for breast and cervical. Therefore, the Colorectal Program was built on the expertise of the Breast and Cervical Cancer Program but with a big shift in business processes. Funds were limited to about 33% of the awards given to grantees can be spent for screening. It was emphasized to grantees to use evidence-based, population strategies in order to impact policy and organizational-level system changes in order to have a multiplier effect. With the passage of the Affordable Care Act, the Colorectal Program will provide examples of how to move forward with the Breast and Cervical Cancer Program.

In putting together the FOA that started last year, there was a need to build a framework that gave flexibility in how business processes worked. With the Affordable Care Act, the focus has been on the screening provision and screening promotion at the population-level. The main question is how best to reach that goal.

The importance of a public health screening system has been continuously stressed as well as evidence-based interventions. So how can they be used together? Screening by itself is not adequate. An organized system will identify who the women are and proactively bring them in and make sure that they have the follow-up needed. The Community Guide has identified evidence-based strategies, and the USPSTF provides guidelines as well as questions and answers for screening. There is the client reminder system that can be designed and used on a larger scale. Reducing structural barriers is another evidence-based intervention as well as provider reminders and provider feedback. There is also the importance of how to influence others to do the same.

To make a difference on a population-level, the programs have to bring the right partners to the table and influence their decisions and behaviors. Who are the right partners for the programs to work with? And how can they effectively influence those partners?

The programs also have to move away from a business-as-usual approach if it wants to get more women into services. There is a need to identify new ways to do business and to break out of the comfort zone.

The committee was left to answer two questions for the program:

- How can the NBCCEDP effectively impact health care system change to increase high-quality cancer screening on a population-level with a special focus on those newly insured?
- What are strategies CDC should consider to address the challenges of evolving a well-established direct screening provision program to embrace health systems change?

#### **DISCUSSION #1: HOW TO APPROACH HEALTH SYSTEM CHANGE**

J. Mullen: I notice you used the term health systems and health care systems and you differentiated between the two. We should do the same in our discussions. We need health system change in the future. It's much more about what happens outside the medical care system. The systems change need to be influenced by a lot of people who aren't just the medical people, but those others who work within, use, and work alongside the system. One of the reasons I asked staff to talk about the match and maintenance of effort is because of health reform. We addressed that issue in Massachusetts. This discussion for me is important because there's a real challenge for public health to demonstrate the roles beyond being regulators. For those who thought it was the safety net provider, then this can become expendable work. The other challenge is we're trying to change a health care system into a health system, which is complex.

P. Wilcox: Are you expecting us to generate recommendations that you can take to Congress and change laws?

F. Wong: We're looking to you to inform some of the decisions on where the program should go in the future.

J. Mullen: We want you to give us permission to be as out of the box as necessary.

- C. Oliveros: There was a division at CDC responsible for capacity building. Is that still active?
- F. Wong: That's integrated in the branch now.
- C. Oliveros: I think it is key to the effectiveness of your reach. It has to be a comprehensive reach with models that address behavior change and will require technical assistance and capacity building with hospitals or the private sector.
- F. Wong: I think you are right. Who do we partner with to do that?
- C. Nandi: Collaboration and communication are two things I am thinking about. We need to collaborate with each other. It's difficult to collaborate with Medicaid, get access to their data, and talk to their leadership heads. And we need to collaborate with the private sector. If you don't have communication or knowledge of what other partners are doing, you can't collaborate effectively. This can also be applied to insurance companies and public programs like Medicaid and Medicare. As far as communication, I wish the medical community was more knowledgeable about the medical system. They are not trained to think about prevention, only treatment. They don't think of their client as a whole person. They only think about the treatment of the disease. Medical education can overcome that. Patients tend to listen more to their doctor than to public health. I think those are areas to think about strategies. We need to close these gaps. We also need to think about culture and having cultural competency for our changing populations.
- J. Mullen: I like the comment you made also about public health and Medicaid communicating.
- S. Taplin: I think the Affordable Care Act is going to force some system change. One key communication piece is to get away from the idea of thinking that this is a safety net program. It is demonstrating what it means to have quality delivery. Our challenge is to screen well and deliver quality screening to the nation. So you all can set the example for the nation of what quality screening means and how to do that. The second thing you should do is change the nature of your program. I don't think it makes sense to have the breast and cervical program separate from the colorectal program. They both have the same challenges; bring them under the same umbrella.
- E. Myers: There are formal methods for deciding what you need to know. Given the uncertainty of the economy, you need to identify those programs that will have the most impact.

- H. Reynolds: Part of the reason we see disparities is because we view breast cancer as one disease, and traditional screening is not going to get you the results you're looking for. Breast cancer is now being seen more closely associated to ovarian cancer, so you need to reconsider that if you want to be more effective in your efforts.
- M. Mosunjac: A suggestion would be to query women about screenings when they come to see the doctor for any issue, not just for women-related issues. If they're coming in for the common cold, ask them have they been screened for breast cancer or when was the last time they had their Pap.
- J. Ford: One opportunity is to think about health care systems that are thinking on a population-based level and to think more geographically. Identify people in need of services and create strategies for those services.
- N. Lee: When we started this program in 1991, we had a gentleman from Sweden help us think about a lot of things, particularly with our data set. We might need to look again at Europe, who's had a lot of experience with the public health approach. They have a much more comprehensive system, still believe deeply in public health, and have a robust registry.
- S. Matoff-Stepp: We've been talking about the health centers but that's not enough. You have the National Health Services Corps that puts people in the area of the country where there's the most need. Ryan White has integrated care for HIV positive individuals. I agree with a systems approach, but we need models here that resonate. You might have to brand it a different name that really sells it to the community. It might not be the Breast and Cervical Cancer Program but maybe the Program that Makes Women Live Longer. A big part of thinking about systems is having all these services in one site, someone to help navigate the system, and taking care of all the ancillary needs that a woman will try to take care of before she takes care of herself will help make this more successful.
- M. Leyboldt: We need pathways and linkages to other programs and across systems like diabetes, smoking cessation programs, etc.
- P. Castle: I like the branding idea. I like the new Celebrating More Birthdays campaign. The more we can broaden the services and still maintain the mandate of reducing disparities around cancer and women the more successful we can be. We will also get more for our dollar, and it allows us to bundle our services. We also need to quantify how

moving breast and cervical to the highest of the highest risk is going to give Congress the biggest return on their investment. These things sell if we can put them into numbers. This gives us an opportunity to show off the program.

**PRESENTATION: PERFORMANCE MANAGEMENT**  
**Dr. Amy DeGroff, Program Services Branch, DCPC, CDC**

Performance management involves the continuous practice of several independent processes related to planning, measurement, analysis, and data use to strengthen accountability, improve program effectiveness, and support policy-related decision making. Performance measurement is the process of defining, monitoring, and using objective, usually quantitative, indicators of the performance of organizations and programs on a regular basis

The performance management system began in 1991. In 1992, a feedback report cycle and the MDEs were employed and in 1994 the Data Quality Indicator Guide was developed. In 2005, eleven performance indicators were identified and made priority for performance-based funding to grantees. In 2006, NBCCEDP provided an edit software program to its grantees to produce provider-level reports, in order to address quality issues. The system has evolved over time and is now a valuable system.

The grantees now submit data twice yearly. IMS is the recipient of that data. It is validated and analyzed and reports are produced that are examined at CDC by program management at an aggregate and state level. There are also individual phone consultations with the grantees to look at reports and identify data and quality issues. This cycle is continuous. Below are examples of MDE Reports and Core Indicators.

MDE Feedback Reports			
Report	Description/Use	Grantee-specific	NBCCEDP Aggregate
Edit Reports	Data values and skip pattern checks (validate data quality and format)	✓	
Frequency	Distribution of data values (validate data quality and consistency)	✓	
Plots	Graphical representation of client characteristics and screening outcomes	✓	✓
Data Quality Indicator Guide (DQIG)	Assess completeness of data and quality of services compared to benchmarks	✓	✓
Core Indicators	Core performance measures and histograms to compare performance to other NBCCEDP grantees	✓	
Audit Reports	Identify client records and clients requiring investigation and follow-up	✓	
Management Reports	CDC use to compare measures across all grantees		✓

Core Indicators		
Type	Indicator	Target
Screening Priority Population	Mammography screening age 50 and older	≥75%
	Women rarely/never screened for cervical cancer	≥20%
Timely and complete Diagnostic follow-up of abnormal screening results	Breast diagnosis completed	≥ 90%
	Breast diagnosis completed within 60 days	≥75%
	Cervical diagnosis completed	≥ 90%
	Cervical diagnosis completed within 90 days	≥ 75%
Timely and complete Treatment initiated for cancers diagnosed	Breast treatment initiated	≥90%
	Breast treatment initiated within 60 days	≥80%
	Cervical treatment initiated	≥90%
	Cervical treatment initiated within 60 days (Invasive)	≥ 80%
	Cervical treatment initiated within 90 days (CIN2/3)	≥80%

The performance-based funding process also incorporates a measure of equity. Programs that have the best performance are rewarded for that. Below is an example of the funding report.

# NBCCEDP Interim Progress Report (IPR) Data Sheet

NBCCEDP DATA SHEET: DP12-1205-01				COOP AGREEMENT #	CODE:	PROGRAM:	DATE:	CONSULTANT:
				606	AA	ANDALUCIA	6-Dec-12	Joseph
<b>FISCAL DATA (as of Feb 2012)</b>		<b>2060-5</b>	<b>07703-1</b>	<b>07703-2</b>	<b>07703-3</b>	<b>07703-4</b>	<b>07703-5</b>	<b>1205-01 REQUEST</b>
1	Total Initial Award	\$2,515,000	\$2,600,000	\$2,600,000	\$2,650,000	\$2,700,000	\$2,370,413	\$2,370,413
2	Total of All Subsequent Awards	\$25,000	\$150,000	\$15,000	\$4,500	\$0	\$0	\$1205-01 AWARD
3	Total Federal Funding	\$2,540,000	\$2,750,000	\$2,615,000	\$2,654,500	\$2,700,000	\$2,370,413	\$2,410,560
4	Total Amount Spent	\$2,530,000	\$2,748,600	\$2,603,000	\$2,653,000	\$0		EQUITY
5	Spending Rate	99.6%	99.9%	99.5%	99.9%	0.0%		AE
6	Remaining Unobligated Balance	\$0	\$0	\$0	\$0	\$0		
7	Estimated Unobligated Reported							
<b>SCREENING DATA (Oct 11 MDE)</b>		<b>2060-5</b>	<b>07703-1</b>	<b>07703-2</b>	<b>07703-3</b>	<b>07703-4</b>	<b>07703-5 PROJECTED</b>	<b>1205-1 PROJECTED</b>
8	Screened	7,000	7,900	8,000	8,800	9,000	9,500	9,700
9	Screened for Breast Cancer	5,500	7,200	7,400	7,750	8,000	8,500	8,700
10	Screened for Cervical Cancer	7,650	5,995	6,250	6,900	7,000	7,500	7,600
<b>DQIG PERFORMANCE</b>		<b>Item:</b>	<b>Oct 09</b>	<b>Apr 10</b>	<b>Oct 10</b>	<b>Apr 11</b>	<b>Oct 11</b>	<b>Apr 12</b>
11	Breast Diagnosis - COMPLETE	20a	MET	MET	MET	MET	MET	MET
12	Cervical Diagnosis - COMPLETE	11a	MET	MET	MET	MET	MET	MET
13	Breast Diagnosis - TIMELY	25d	MET	MET	MET	MET	MET	MET
14	Cervical Diagnosis - TIMELY	16d	MET	MET	MET	MET	MET	MET
15	Treatment of CIN Diagnosis - TIMELY	18d	MET	MET	MET	MET	MET	MET
16	Treatment of Inv Cervical Cancer - TIMELY	18g	MET	MET	MET	MET	MET	MET
17	Treatment of Breast Cancer - TIMELY	27d	MET	MET	MET	MET	MET	MET
18	Mammograms to Women Over 50	19e	MET	MET	MET	MET	MET	MET
19	Cervical Rarely or Never Screened	6a	MET	MET	MET	MET	MET	MET

Month	Value
Oct 09	9
Apr 10	9
Oct 10	9
Apr 11	9
Oct 11	9
Apr 12	9

Item	2060-5	7703-1	7703-2	7703-3	7703-4	7703-5	1205-1
Breast Screening	~\$2,540,000	~\$2,750,000	~\$2,615,000	~\$2,654,500	~\$2,700,000	~\$2,370,413	~\$2,410,560
Cervical Screening	~\$2,540,000	~\$2,615,000	~\$2,615,000	~\$2,654,500	~\$2,700,000	~\$2,370,413	~\$2,410,560

There is a need to study the NBCCEDP Performance Management System because there has been wide adoption of performance management in the government and beyond. The NBCCEDP completed the implementation of a comprehensive performance management system in 2006. Some grantees have implemented similar approaches, but there has been little research evaluating the effectiveness of performance management systems. The program has finished one study and another one is underway. Two studies examine the change in performance following implementation of the CDC performance management system. There has also been an evaluation conducted of Colorado's bundled payment system model.

There are several research questions to be answered such as:

- Is the NBCCEDP performance management system effective in improving program performance?
- What are the key characteristics of the NBCCEDP performance management system that might explain why the system is, or is not, effective?

- What are the impacts of the Colorado bundled payment system on breast and cervical cancer screening and diagnostic services?

Quantitative results suggest that the NBCCEDP Performance Management System is effective. Also, the qualitative results help explain its apparent success, such as characteristics of the NBCCEDP program, qualities of the indicators used, investments made in the system and resulting capacity developed over time at CDC and among grantees, and culture of performance data use.

The Colorado bundled payment system is intended to improve screening quality. It is a modified pay-for-performance/outcomes-based reimbursement model and rewards providers who deliver quality health care services and contain costs. Reimbursement is based on attainment of a definitive diagnosis within a specified time period and the complexity of individual patient cases. The research question to be answered is: What are the impacts of the Colorado bundled payment system on breast and cervical cancer screening and diagnostic services?

Another project being worked on is with the Community Health Care Association of New York (CHCANY). It was funded in July 2012 to develop an electronic interface for FQHCs with screening data directed to a statewide data warehouse, which will basically serve as a cancer registry for FQHCs. This provides actionable data via reporting back to FQHCs at an individual level. Quality metrics are under development and eventually will include a cancer screening dashboard with targets.

## **DISCUSSION #2: ENHANCING POPULATION-BASED SCREENING THROUGH MONITORING**

J. Mullen: So we're looking for a new framework and it's not just about the technical data. It's also about how you measure. I don't want this program to be measured by how many cancers are diagnosed or screened. What is also important is how these programs fit in with other services. It's about quality and measuring equity.

S. Taplin: You also establish metrics that demonstrate what you're doing for each of your populations. We can compare to make sure you're delivering the same care across territories.

P. Lantz: When you see performance issues, what other tactics have you used in addressing those?

A. DeGross: States have taken different approaches including dropping a provider's contract.

M. Leyboldt: Some states also do audit checks and education. We see problems in providers when there are changes in the program and

they haven't been fully educated on how to work correctly within new program modifications.

- J. Mullen: Another thing we see is that every time there're multiple site visits, you wear out the same people. We need to do things more efficiently. I have sat in meetings where people raise concern about doing work for the sake of the program versus for the sake of the population.
- M. Leypoldt: Another thing we can do is find a way to use the data differently. These women are still there, so there's an opportunity to provide different types of data.
- A. DeGross: We are also paying for navigation services, so we could develop a dataset around navigation.
- J. Ford: We found the need for an electronic system that can guide people through navigation.
- S. Taplin: When there's a low rate of screening, the question is: Was screening offered? So begin to document a way of how the screening element occurred.
- N. Lee: Text for Babies and mobile technology might be something you could develop for navigators. Challenge.gov has people who compete to win prizes to develop these mobile technologies.
- S. Matoff-Stepp: We were some of the early adopters of mobile health and using MHealth, Twitter, Face Book, etc. so that we can put the power in the hand of the provider, woman, or the navigator to use the technology that we're a part of and see what we can do with it.
- N. Lee: There are things in the federal government that support these things.
- J. Mullen: We used Text for Babies for carbon monoxide poisoning alert, so it can be catered to this program.
- J. Mullen: Have you taken the screening promotion to the population level and done much with it? Do the MDEs measure this or what does that look at?
- A. DeGross: We're looking at new demonstration projects. It's going to be a while before we can really measure. We have created some strong evaluation designs to see if we're finding population-level changes in the data for the colorectal program. So we have something like that large scale to measure for a population-level based screening.

- J. Mullen: Are there things from Healthy People 2020 that can inform some of this work?
- A. DeGross: Focusing on policy level or system level strategies will focus you towards the best change.
- F. Wong: And I think Healthy People 2020 are examples of things that define what our vision should be and point us in the right direction. But we struggle with how do we make the right steps.
- P. Lantz: Hospitals are going to require community needs assessments and this will provide a good opportunity to tie them into health systems.
- A. DeGross: We can do a lot of program monitoring, but we really want to look at impact.

**PRESENTATION: BREAST CANCER MORTALITY DISPARITIES  
Dr. Jacqueline Miller, Program Services Branch, DCPC, CDC**

CDC recently published an article in the Vital Signs that looked at racial disparities in breast cancer in the United States from 2005-2009. Nearly 40,000 women die of breast cancer each year in the U.S. Black women are 40% more likely to die of breast cancer than white women, and nearly 1,800 fewer black women would die of breast cancer, if death rates were the same as white women.

A fact sheet was developed to address steps to timely follow-up and improved access to high-quality treatment. It provides instructions on what to do if a mammogram is positive and what entities should be involved in follow-up and treatment. The fact sheet goes beyond screening and talks about the whole continuum of care.

Projected changes in insurance coverage will cause shifts in statistics for breast and cervical cancer program population. Below are some projected statistics published by Dr. Leighton Ku.

## Projected Changes in Insurance Coverage

	Breast Cancer	Cervical Cancer
Variable	Women Aged 40-64	Women Aged 18-64
Uninsured women in 2009, in thousands, n (%)	4,514 (31.1)	11,266 (33.6)
Projected uninsured women in 2014, in thousands, n (%)	1,705 (11.2)	4,470 (12.9)
Projected increase in insured women from 2009 to 2014, in thousands, n	2,809	6,796
Projected annual increase in cancer screenings due to increased insurance coverage in 2014, in thousands, n	500	1,300
NBCCEDP-eligible women projected to be screened in 2014, %	30.3	17.5

Levy AR, et al. 2012

There was also a need to identify the distribution of this population with the changes in insurance coverage. Below are expected shifts in population percentages.

## Characteristics of Women Eligible for NBCCEDP

	% Total, 2009	% Total, 2014
Hispanic	32.8	<b>39.2</b>
Black	16.3	12.8
White	44.0	39.4
American Indian	1.3	0.9
Asian	4.1	<b>6.1</b>
Without High School Degree	28.5	<b>32.6</b>
Limited English proficiency	25.3	<b>33.2</b>

\*Table describes uninsured women ages 18-64 with incomes below 250% FPL

These statistics indicate that there is still a need to identify ways to address breast cancer disparities. Therefore, the question posed to the committee from the program is:

- What should be the NBCCEDP population–based focus/strategies to combat disparities in breast and cervical cancer?

### **DISCUSSION #3: APPROACHES TO DECREASING DISPARITIES**

- J. Ford: It's clear that there's going to be a need for culturally-specific strategies. That needs to be done regionally and requires communicative modules so we can find these people as they touch the health system. And it may even require going outside of the health system to where people are, like hair salons for example.
- P. Castle: And we need to understand the psychosocial aspects of reaching them. We need to be out of the box with these strategies. There may need to be incentives involved to get them, which may not be financial. We can frame this as quality improvement.
- P. Castle: And we have to expand community health workers to get people in as well. They are instrumental and are the primary interface between the patients. They help to get them into primary services.
- Y. Green: What were the lessons learned from the African America program you did some time ago with Ingrid? You could use that.
- P. Castle: Right, it's going to have to be culturally tailored, and it may require doing focus groups to do that.
- S. Taplin: Before we go outside the box, we need to glean from some of the people here around the table and find out what they've already learned like what we've learned at NCI.
- J. Ford: I don't know if the work that NCI does is really going to be good for this community.
- M. Plescia: We've been doing Vital Signs since Dr. Frieden came here and it takes on the issue of disparities. That is one area that the breast and cervical program can look at in a little more depth. One question to answer is: Where should our focus be, and are we in a position to put some of these disparities to rest?
- M. Leypoldt: We should look at how we engage communities. We are providing resources to communities to do things that they know work.
- H. Reynolds: Would it be better to track the number of women we educate because screening is a personal choice?

- P. Castle: When you say 40% increase death, where is the breakdown?
- M. Plescia: There are a whole lot of socioeconomic issues that play in that. We choose the area we can have control over, but the question is: Are there things missing.
- P. Castle: We should look at how many women get screened and control by age, stage, BMI, etc. so we can start to understand this data.
- J. Miller: In the study we did reference that black women have a longer time between diagnosis to start of treatment and some other factors that go along with that. So we do reference those things.
- P. Wilcox: Is it because the care provider doesn't come back quickly enough or is it that the women don't follow through with follow-up quickly enough?
- M. Plescia: We frame the answer to that carefully. It's a little of both but from the woman's stand point. Her lack of follow-up is because the health care system can be very complex to navigate through.
- E. Myers: It would be good to focus on the health system instead of looking at all the competing things happening outside of the health system.
- P. Lantz: When you talk to policymakers, they think it's all biology and therefore there's nothing we can do anything about that. We have to stay the course and convince them that there are so many social aspects involved. For example, the first dose of chemo is based on weight, and since African American women tend to have higher weight, they may be under-dosed—things like that.
- H. Reynolds: I would encourage you not to minimize the biology. It is a big piece of this. It is real. Screening is not a magic or silver bullet. We should inform and educate women to recognize why outcomes will be different.
- P. Castle: As an epidemiologist, a lot of the markers are not strong enough to be used for clinical indicators. Biology is important, but there are things we can prevent that have to do with the human element.
- J. Ford: I'm not sure what proportion is explained by biology, so I don't want to overplay the role of biology.
- J. Mullen: I want to make sure we get to thinking about what can be done to address breast cancer disparities. We have to advise CDC as to

where this program should go, and this is the time to create the systems for women to be healthy. There's never going to be enough money, so the ability for us to affirm the work that you did in Vital Signs and put an exclamation mark behind it could be helpful. I think that's the direction we should go. Let's charge people with owning this. Let's think about the other systems changes and other performance measures. Are there other recommendations that we need to do?

S. Taplin: I think there is an important message that comes out of the bio-science piece. We need to also figure out how to say you need to start with screening but that's not enough. You got to go further so that we don't create unrealistic expectations. Screening is a process and screening is not the only answer.

J. Mullen: One of the things we've talked about a lot is strategies that need to be employed to reach some of these groups, and we're at a time where people are looking at new payment models. Are there any other things we might think about regarding how care is delivered in a setting?

P. Castle: The model is changing. Surgeons get paid more than the community health worker. You do not need a nurse and a clinician to take a Pap sample. We are going to be hard-pressed to continue at spending 20% of our gross product in health care, so maybe that is part of the national discussion is how to expand the role of the health worker out into the community.

E. Myers: And maybe having to go where people are, like giving Paps at the Walgreen's for example.

C. Nandi: That is true. We should not expect people to come to us. Even church, temple, cultural functions, etc. We also will not have enough physicians to take new patients now that they have insurance, so that will be a big challenge. There should be a mid-level care practitioner that can do regular maintenance health and let the physician can do higher level health. The community health workers are a lot more culturally competent. They know the people. They speak their language. They can get them engaged.

J. Mullen: Are New York sites using community health workers?

D. Joseph: We did not get into how they're reaching their population. It was establishing their registry. They often find screening rates are low because they're not screening or not documenting.

- P. Wilcox: In the 60/40 programs, do they all have navigators?
- F. Wong: No, not all of them.
- P. Wilcox: Have you done comparisons of the turnaround times using navigators versus not using navigators?
- F. Wong: We don't have that kind of data at this point in time. We saw improvements when we started tying performance to funding. CDC is in the process of expanding patient navigation. I don't think we have specific information on whether it saves time on diagnosis to treatment.
- P. Wilcox: You have to have some hard measures. These economically disadvantaged populations need someone who can explain and hold their hands and walk them through.
- M. Leypoldt: We looked at staging for clients in our program specifically for African Americans. The difference for us was case management, and we're talking about making sure these women understand their diagnosis and are able to make informed decisions.
- M. Mosunjac: There are no guidelines to what should be the guidelines. Lancet in 1999 said there's no difference in survival if the delay of first time of treatment is no longer than three months. Now the problem with the surveys is they lump patients with different margin status.
- M. Dolan: I think the patient experience should be considered and the anxiety and the wait. For us not to consider that is not right.
- J. Mullen: Yes, and if you ask people their perception of care, wait time is perception of their quality of treatment. Also, if you were trying to decide what hospitals might do to help supplement that 40%, what would you suggest?
- P. Lantz: I haven't thought on that level, but it would be community-specific.
- J. Mullen: Hospitals are looking for help in thinking that through.

#### **KEY RECOMMENDATIONS TO CDC**

- E. Myers: Look at performance measures and build up the population model approaches.
- P. Castle: We need a better name to allow expansion as we go forward.

- J. Mullen: So change the name, but still be in the funding box. It will create some flexibility for funding. Think about how we can articulate more funding flexibility for the program.
- M. Leypoldt: The target audience for this name change is really Congress. Am I right?
- P. Castle: I don't think so.
- J. Mullen: There's the outreach piece. As an advisory committee, we're making recommendations that will get implemented nationally.
- M. Plescia: One of the things that CDC is working on is providing flexibility so that grantees can use funding across chronic diseases in a more flexible way. There are concerns about a lot of the funding and some of the risk that we can incur with that. Some advocacy groups were concerned with it, but we came away with the understanding that states do need more flexibility on this. We are getting at that from CDC leadership but funding is tricky.
- J. Mullen: A way to not revisit that problem is to remember that there's funding money and state money for this program. In this program, there's more than one bucket of money, and there are ways to coordinate the effort. A recommendation is to recognize that there's more than just the federal dollars, and, therefore, they should look at other ways to fund.
- J. Ford: And brand statewide programs as they see fit.
- P. Wilcox: Consider ways to optimize nonfederal funds across the programs, which they seem to be doing.
- P. Castle: And broaden it to women's cancers because obesity is going to be a more important cause of cancer. And this will open the box for those things that can affect women's health and provide more comprehensive care to underserved women. Now with ACA, it's going to be the worst of the worst in terms of risk.
- J. Mullen: So optimize nonfederal dollars for other cancers.
- P. Castle: Right, this is the cancer program and we're getting cancer dollars.
- S. Matoff-Stepp: There's a great commercial out right now by Kaiser where a person comes in for a cold and they walk out with an appointment for their mammogram. So the thought of integrating services. When she's coming in for diabetes, take advantage of that moment to check to

see if she's had her mammogram and cervical screening. Prompt the health care system to engage women. A woman is busy, so capitalize on that time when you have her in your presence.

P. Castle: There's a list or checklist of what could be done at that well woman visit.

N. Lee: We can use that model to set up the guidelines for the well-women visit. There's also someone here at CDC that's doing something for the preventative visit, and I can figure out who that is. My understanding is that the people at the federal level are not going to get down in the weeds about this and want to leave a lot to the states and health departments. So it's important to have the evidence base that states can draw upon. CDC needs to define what the well woman visit is, and you can hang all those other prevention services around that.

P. Lantz: Our team is looking at electronic systems that alert when patients are due for certain tests or screenings, so maybe we need more app development. What other services are women due or eligible for? We can take advantage of technology to alert them to that.

J. Mullen: There was talk about navigators, so do you want to put a recommendation on that?

P. Lantz: I think patient navigation could be added to that 60%.

M. Leyboldt: And I think a lot of states are having a hard time defining the difference between the community health workers, patient navigator, and case managers. For each of those, we need to make sure these people have credible jobs and credible wages so they can get paid for those.

J. Mullen: And could some of this also be afforded by the 40% as well because some of the conversation is about taking care of the whole woman. A community health center may want to have community health workers as a part of the wrap-around portion.

P. Lantz: But the more you put in the 60% the better, so it should be in the direct bucket.

J. Mullen: Well then let's modify that recommendation.

F. Wong: I don't know if you all should get too worried on that part of it.

C. Oliveros: I think CDC can position themselves to train and identify new evidence-based strategies.

J. Mullen: Steve said to move away from this being a safety net program.

M. Leypoldt: I agree.

J. Mullen: The other recommendation was enhancing population management through monitoring.

M. Dolan: I think we said expanding some of the indicators.

P. Wilcox: You said there's more paperwork. There needs to be more technology to support the collection of the data.

J. Mullen: Amy, do you have any further input on the administrative burden piece?

A. DeGross: If we use the data effectively and show it back to the people that collect it, they then will be okay with collecting the data. If you're going to burden them, show them how it's being used and use the data effectively.

M. Dolan: It might be nice if states could see how other states are doing with their data.

A. DeGross: We have that, and we have the QSST meetings, so there is sharing across programs. We can implement more and facilitate more.

J. Mullen: So using some of that data to educate people on how effective this program has been. Is there a recommendation in that regard?

E. Myers: In terms of feedback to providers, what elements are important for comparison and are important?

A. DeGross: We can work with them on how they collect similar data.

P. Castle: Drive the message home. People respond to the C word. People dying of cancer gets a person thinking.

N. Lee: I have never been able to measure the mortality effect, but we looked at cancer registries and now have better state registries in many states so you can do abstractions. That might be one way to demonstrate the value.

- J. Mullen: Evan also said to use what's available to prioritize what happens in the program going forward.
- E. Myers: You can look at where the greatest area of uncertainty is and those areas that aren't adding much to the research.
- M. Leypoldt: We also talked about exploring opportunities to collect data and what that data should look like,
- J. Mullen: Let's move on to approaches to decreasing disparities?
- J. Ford: I think we have to measure them first. I think we should measure them throughout the entire spectrum of care.
- P. Castle: We need more details to understand the 40% disparities and we can hone in on where we need to fix the problem.
- J. Mullen: Was there anything in social determinants we wanted to state?
- M. Leypoldt: Share with the community what you found so they can be a part of that process of identifying the gaps.
- P. Castle: And engage the community on how to solve the problems and reduce disparity.
- P. Lantz: If we're focusing on breast cancer mortality disparity, the MDEs should be expanded. See what are the experiences of women with treatments and do pilots.
- P. Castle: So, these are sentinel sites to give us more information.
- A. DeGross: All states are linking their cancer cases and we can go with registries that are more prepared.
- M. Leypoldt: There's not a repository of those studies or outcomes, and a repository might be helpful.
- H. Reynolds: With the implementation of ACA, the population will change so new strategies will need to be sought out.
- J. Mullen: And there was a recommendation to put more money into the program.
- P. Castle: We could be much more active for women who are not being screened and for their daughters by utilizing self-collection for HPV testing. It saves one clinic visit. Women were more likely to select it.

- H. Reynolds: It's a whole other issue to get these women to submit their daughters and sons for these vaccines. They are very skeptical of the medical community.
- P. Castle: There has to be education in all of this and training. We have to educate them on the importance of it. It's going to come up through the NCI in the President's Cancer Panel.
- P. Lantz: Insurance companies will negotiate a better price for it too.
- P. Castle: If we create the education that creates the demand. Then there's a greater incentive to negotiate the price.
- P. Lantz: And these have to be community-based participatory approaches.
- J. Mullen: I like the idea of a long-range strategy in all of this.
- S. Matoff-Stepp: Women's health and men's health you can't totally separate them. Where do men and boys fit into all of this in terms of support systems? It's important to engage men in this effort. If women are not around, men don't thrive. Data show that men do better when they're married.
- S. Taplin: A male breast cancer piece is needed also, so there should be an education piece to that respect too.
- P. Wilcox: This is very important for the Latino population so that the men can empower their women.
- J. Ford: And in other cultures.
- P. Castle: And men can be the "navigator".
- M. Leyboldt: Anything done in terms of system changes affects everyone that walks in that office, not just the women.
- J. Ford: With health care systems, there should be strategies to address the needs of under-served and to monitor performance in relation to that population.

## **PUBLIC COMMENTS**

[No comments from the public.]

**WRAP-UP/ANNOUNCEMENTS**  
**Jewel Mullen**

I appreciate everyone's participation and I look forward to continuing our discussions tomorrow.

**ADJOURN**

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## **FRIDAY, DECEMBER 7, 2012**

Ms. Jameka Blackmon called the meeting to order and conducted a roll call to ensure that quorum was met. The following were present.

- Dr. Jewel Mullen
- Ms. Jameka Blackmon
- Dr. Phillip Castle
- Dr. Mary Dolan
- Dr. Jean Ford
- Dr. Paula Lantz
- Ms. Melissa Leypoldt
- Dr. Marina Mosunjac
- Dr. Evan Myers
- Ms. Chandana Nandi
- Dr. Catherine Oliveros
- Dr. Handel Reynolds (By Phone)
- Ms. Yvonne Green
- Dr. Nancy Lee
- Dr. Sabrina Matoff-Stepp
- Dr Richard Wild
- Dr. Carol Brown (By Phone)

## **Highlights and Review**

### **Jewel Mullen**

Dr. Mullen stated that she felt yesterday's discussion provided a highlight and review and decided to go straight into the day's presentation on health reform.

### **PRESENTATION: PUBLIC HEALTH NICHE**

#### **Mike Mizelle**

The law authorizing the program is fairly descriptive with the 60/40 Rule being the biggest requirement. Changes brought on by the Affordable Care Act will significantly decrease the number of women eligible for the program, but studies also show that there will still be a need for a direct screening component. Grantees will also be affected in different ways because of the implementation of the Affordable Care Act. The program has been working on ways to transition and to define public health roles for the future, but in order to do this, the program needs more flexibility in how it operates and allocates funding. This will probably be through appropriations language.

The program has talked about expanding the waiver option to all grantees and that may offer the flexibility to grantees. It cannot summarily make these changes on its own. Congress and the Administration are looking for places to cut federal spending, and the Affordable Care Act is a double-edge sword that offers its own opportunities and challenges. Programs could be viewed as unnecessary in the future.

In the past it's been easier to sell a program that provided screenings and detects cancers, but that is no longer the case with the screening provisions included in the Affordable Care Act. The program therefore needs to sell to policymakers why their population-based efforts are still needed in the future. There is an obligation to find a public health niche to increase quality screening and enhance the value of the benefits of the Affordable Care Act.

The program hopes that the committee can help make a case in three ways:

- Focus in on four or five key roles for the program moving forward to identify core principles of components to incorporate into reauthorization discussions with policymakers.
- How to sell the benefit or value for these investments in the future.
- Help to make sure policymakers understand why the program needs to be flexible in order to be most effective going forth.

#### **DISCUSSION #4: NBCCEDP CHANGES AS AFFORDABLE CARE ACT IS IMPLEMENTED ACROSS STATES AND IDENTIFYING A PUBLIC HEALTH NICHE**

E. Myers: What the program has done is taken a pool of resources for people who didn't have access to them and made those resources available. That's the big picture of what the program can offer. The program's value is getting people into screening and then getting them into treatment.

P. Lantz: I have a question about the 60/40 waiver. What are the terms of the waiver?

M. Mizelle: It is pretty prescriptive. They had to show they were screening at the same level or increasing screening in their state. They were only given up to two years and then they could reapply for another year. That wasn't a lot of time to show results. Fiscal challenges were a barrier to doing that. So we thought about that in reauthorization.

P. Lantz: The waiver doesn't sound like the best policy option.

F. Wong: The law requires grantees to be compliant with 60/40. It would be helpful if CDC could approve waivers as appropriate. Opportunities are there and needs are there, so flexibility is needed.

P. Lantz: Why not go back to a different formula?

M. Leypoldt: Coming from the program side, the waiver is not situational. It's a temporary fix. It would be more helpful to have the flexibility to say what goes into that 60%. If the whole range of navigation could go into that 60%, that would work.

- N. Lee: I'll go back to the benefits of an organized screening program. If it could be used for all people enrolled on Medicaid as part of a way to follow them along with the screening; that will be beneficial. You can sell this. We have proof that organized screening works in difficult populations. I don't know if you need the 60/40. If not, then you might not need so much money so if you get the cut, it won't affect you so drastically. Do what they do in Sweden. That's real rethinking.
- P. Castle: We're now talking about switching people to a new system, which I'm not sure what that looks like. My first thought is: Why change it? You shouldn't change something that's already working. Just fund what works. These are disenfranchised populations. They already have relationships and trust with their providers. Let them stay with their providers and figure a way to fund the community health centers. Secondly, this comes back to a health investment. This is more cost-effective than letting people get cancer. We need to make the case that we're preventing deaths.
- M. Dolan: You have evidence that you have an effective program. I think you can do a business argument that this is a quality initiative and continuing to follow these patients is important.
- M. Leypoldt: The only thing that changes is the ability to pay for clinical services. Maybe it becomes "Who's the payer?", but you could collect and do all those things that the program does the best.
- E. Myers: You can't make an argument that screening saves money.
- P. Castle: We know that this program is successful, and this population is going to be squeamish about changing this program. The insurance company could funnel the money through a program that's already working.
- J. Mullen: So we are starting to talk about a certain kind of fee-for-service program. We need to think about how health care providers deliver this program.
- C. Nandi: Public health already has infrastructure. They're good at what they do, and are in a position to do ACA. They're better positioned than private insurance. And changing insurance is a headache. Another thing is with this influx of new patients due to ACA, where are they going to go? Will private insurance have the capacity to take all these new patients?

- P. Castle: And these populations have already trusted relationships with these physicians for these personal examinations. We might do more harm than good by switching them.
- C. Nandi: And you can add Medicaid, Medicare, private, public, just add a few more categories—this will make us much more successful.
- J. Mullen: What is the prospect for having CMS make a case for the way the B&C needs to morph or evolve? How does the message around the rest of the transformation transfer to this as well?
- F. Wong: I think it's a great idea to suggest we have some broader discussion with CMS. Our conversation so far has been around protecting treatment availability. The people we have been talking to are very supportive and are for the continuation of the Treatment Act with no changes with regard to availability.
- J. Mullen: Can they amplify the need to do something past the 60/40?
- F. Wong: I think the important message out of this group is flexibility.
- E. Myers: There are opportunities to be a model and for public and private partnerships. Position the program as one that can work within the new system as a laboratory or as a sample of how to get good outcomes. That will resonate with Congress.
- C. Nandi: Another plus would be the cancer registry. You can enhance the data to add a treatment component.
- N. Lee: I like the idea of the innovation centers. Organized screening pulls in some of that. With reauthorization if you change it too much, you may lose the whole thing.
- R. Wild: CMS conducted research, at the instruction of Congress, to do rapid cycle testing looking at promising ideas and implementing them. We have funded many innovation projects. We are waiting to see results, and how to implement them down the road. There are some members of Congress who have reservations about that process and want to have more oversight of that. That was the whole plan of the ACA, to give us more flexibility, and it will continue to be scrutinized by Congress as they look at where money is being spent.
- J. Mullen: Another recommendation is to focus on underserved populations in certain geographical areas or building capacity in safety net providers. There's been talk about getting to the hard-to-reach

population. We have Vital Signs from yesterday. Is there anything we need to be talking about in terms of focus?

- J. Ford: It could be done at the level of the health care system, from screening all the way through diagnosis as well as in terms of the measures. I also like the idea of a safety net focus as well.
- J. Mullen: How do you all feel about making a recommendation to address disparities and look at geography and race and ethnicity within it?
- P. Castle: I strongly favor it.
- E. Myers: I think it helps with decision making and puts policymakers on the spot.
- P. Lantz: And there should be a modeling exercise to demonstrate what would happen if this program went away. That would show impact.
- P. Castle: And another to show the impact of the program if it expanded.
- M. Leypoldt: I see a huge loss if you looked at that. The Plains states are not going to adopt Medicaid expansion. A lot of states are not going to be helpful to make sure vulnerable populations get to the services they need. It's not in their best interest to do so.
- J. Ford: It's about things being functionally accessible and not just available.
- S. Matoff-Stepp: I don't want to paint the picture of women as victims either. There're gaps and challenges, but there are women who do make it. They can serve as teachers or peer models for other women. That's too stereotypical a view and doesn't show how resourceful they can be.
- R. Wild: As people see the implementation of the ACA, there might be heightened awareness of those who do not have health benefits. That may be a significant driving force.
- J. Mullen: Also, language is important for lots of reason. We don't want to use language that allows people to write this off.
- Y. Green: Would this be considered insurance for those who don't fit the insurance mode?
- J. Miller: States are asking how are they going to be able to pay for certain things. So, as an entire program, how do we work with that? We're trying to figure that out. Some of this comes down to definitions.

- Y. Green: How much does that happen?
- J. Miller: It happens, not as much right now. And it's always a struggle, but they're realizing it may be a larger percentage of the people they will come in contact with.
- P. Lantz: For people who have really large deductibles, it might to be a problem.
- N. Lee: So, for the underinsured, you might still have to pay these co-pays?
- M. Leypoldt: We pay up to the Medicare rate and the provider has to write off the rest.
- N. Lee: I'm not sure why this would be the problem. You're only paying for the co-pays and you could raise the eligibility of the underinsured.
- F. Wong: We fund it as un- or under-insured. But states do have some latitude on that.
- R. Wild: You pay first dollar if they haven't met their deductible?
- M. Leypoldt: If they have not met their deductible, we pay it.
- C. Oliveros: Have you done an analysis based on the ACA and the impact it will have in their communities?
- F. Wong: We have not done a study because we are trying to figure out what health reform is. Taking a look at it more formally might be appropriate.
- M. Mizelle: You brought up looking at the map and thinking about disparities. That lends itself to helping us with the broader flexibility argument, but I would caution on how specific we get on that.
- P. Castle: We can hang this as a needs assessment.
- M. Mizelle: Right. That is important and it's sellable.

**QUESTIONS AND COMMENTS FROM THE PUBLIC**  
**Jewel Mullen**

No comments or questions from the public.

**REVIEW OF RECOMMENDATIONS/IDENTIFYING NEXT STEPS**

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J. Mullen: So we're at the point where we identify recommendations and determine concrete steps. We have a lot of text from yesterday. But let's make recommendations with regards to the ACA.

E. Myers: The program should evaluate impact by linking program data to mortality data. Look at women who died and see if they participated in the program.

N. Lee: And look at possible comparisons.

E. Myers: That builds the argument that the program is a model for everyone.

N. Lee: And it's the whole point of organized screening. It puts everything in place so that you get reduction in mortality.

P. Lantz: I don't see the program design here.

E. Myers: This is an estimate. We're suggesting it to show the potential.

J. Ford: It can also address stage at diagnosis.

E. Myers: And the program before diagnosis and treatment.

J. Mullen: We might not want to get into study design. Your recommendations are things that CDC can demonstrate and make the case for sustaining the program and for organized screening to be part of the program.

P. Castle: It's an expansion to look at the effectiveness of the program.

P. Lantz: What would play well in Washington is packaging it as a formal policy options analysis. Here's what the world would look like status quo, and here's what it looks like if it went away. Then you could have, maybe, a couple in between. This would allow for comparing and contrasting.

J. Mullen: Are there any other groups we would like to involve so that it's not just CDC?

P. Lantz: I have a group of students working on this.

J. Mullen: Any payers, hospital associations?

F. Wong: What's useful is doing research to look at options, and we'll figure out the how.

- S. Matoff-Stepp: We need to develop consumer education tools because women are the best teachers for other women.
- J. Ford: Perhaps develop and implement strategies for populations at risk for lack of information, such as new immigrant populations. Establish measures for monitoring and addressing disparities within health care organizations through screening and timeliness of diagnosis and initiation of care. I want to think about this on a population level, and we're talking about the population of covered lives.
- E. Myers: Investigate the potential for public-private partnerships to achieve the goals of population-level cancer prevention.
- P. Castle: Funneling ACA dollars into the B&C programs to continue services for women in the program and not change the interface. This is what I was talking about earlier-of people being forced to go to new providers. Instead let insurance companies in some way give the money to the B&C program to continue people with their providers.
- M. Leypoldt: And be inclusive of community health workers.
- J. Mullen: What about refocusing funds towards geographic areas for a consideration?
- P. Lantz: Flexibility so states could do that.
- J. Mullen: So, would you suggest that CDC have the flexibility to do that and put focus on the highest risk?
- E. Myers: One option is continue to focus on populations in geographic areas of highest needs.
- F. Wong: When we designed our new FOA we had some experience with ACA, so we could rewrite it so that states that don't need much help could redirect those funds to those highest risk areas.
- P. Castle: We want to have greater flexibility. Programs should not be held to a particular fraction. The 60/40 ratio may not be right.
- M. Dolan: Or just let the states decide what the 60 includes, may be another way to tackle it.
- P. Lantz: Or it could be a combination of both.
- J. Mullen: What about using CMS innovations to inform program changes?

P. Castle: Yes.

J. Mullen: Anything from the provider community?

M. Dolan: Make it easy.

J. Mullen: Looking over yesterday's work, do you need any clarification?

F. Wong: I think the diversity on this committee is superb and your comments are in line with our thoughts. Some have spurred new thoughts. We'll look at them and put them into buckets. We need to think through them and move forward.

J. Mullen: We talked about if there is a need for subcommittees or subgroups and do you think that is something we need to do to define the problem.

F. Wong: I think we need to reflect first, put them in the buckets, and then seek the advice of the committee.

J. Mullen: Is there anything we want to say that they shouldn't do? One comment was: Why change anything? Mine is: Don't let this program go away and make sure all 67 sites continue to be served.

N. Lee: They have performance-based funding, so you don't want to fund someone not doing a good job.

P. Castle: The program must be preserved at this funding level, if not expanded.

P. Lantz: I think there's political risk saying that.

M. Leyboldt: As we morph into something different, there may need to re-look at what things are included in performance-based budgeting. Some things may no longer fit the mold for that type of budgeting.

J. Mullen: While we don't want to say throw performance measures out, we do want to make sure women's functional access to B&C screening is maintained.

F. Wong: I think looking down the line, we will have a different way of doing business with the ACA, and we'll be able to maximize it.

## **WRAP-UP/ANNOUNCEMENTS**

- J. Mullen: How will we know what you did with the work? What are the next steps?
- F. Wong: We have a recorder who will return notes and the recommendations. We will look at those and all the ideas to see how they inform what we do and we'll provide you with feedback.
- J. Mullen: It's been so nice for me to hear your knowledge and it's extremely encouraging. This conversation is so focused on potentials going forward to get to a better system in this country because of the work that all of you do. This will help policymakers adopt what makes the most sense to us and shift values to what makes the most sense for people and populations. We have decades of engagement in that work among that board. So, thank you.
- P. Castle: And we thank you for being a wonderful chair.
- F. Wong: We recognize everyone on this committee is very busy and thank you for coming to Atlanta to give us very good feedback. It's invaluable. Your passion is evident. And thank you, Jewel, for your hard work. Thank you to all of those who worked behind the scene to plan this meeting.
- J. Blackmon: We will have minutes in the next 60 days and they will be published on the website. The next formal meeting may or may not be via a conference call. We are not sure of the date as of yet. Thank you to callers on the phone and safe travels home.

## COMPILED LIST OF RECOMMENDATIONS FROM THE FLIPCHARTS

### Systems

1. Expanding some of the performance measures to hold programs accountable.
2. Name change of program (B&C is limiting).
3. Make emphasis on prevention vs. screening.
4. Build-up population approaches (logic model).
5. Come up with words people understand vs. "prevention" and "mortality."
6. Create flexibility so program can expand (e.g., name change/re-branding) (include WISEWOMAN).
7. Acknowledge there are more than federal dollars and consider ways to optimize use of non-federal dollars across programs (to address other cancers).
8. Integrate screening into whatever else the woman is coming into care for, looking at all opportunities.

9. Better define well-woman visits. Set up parameters and EHR for visit.
10. Use of digital devices to enable the best version of evidence-based practice (technology).
11. Provide resources, tools, and trainings for implementation of evidence-based strategies to increase prevention, education, awareness, and screening within their population.
12. Add patient navigation to 60% (define community health workers, and patient navigation and case management).
13. Identify new evidence-based strategies.
14. Move away from the notion that this is just a safety net program.

### **Performance Management**

1. Expand some of the indicators.
2. Need more technology to support the collection of this data.
3. Perhaps facilitate better/more communication of data across programs.
4. Compare our quality measures to other quality measures.
5. Make it easier to get data by making collection shorter, simpler when some questions can be eliminated.
6. Need more analysis from patients on benefits of program and getting it out to the public.
7. Be able to describe new population compared to the old population. Understand before and after.
8. Use what's available to prioritize going forward.
9. Explore different opportunities to collect data and what new data would look like.

### **Approaches to Disparities**

1. Measure disparities within health care, assessments across the continuum of care. Need more details to understand the 40% disparities.
2. Quality improvement strategies to address disparities.
3. Share with community what barriers are identified and community engagement on how to address the challenges.
4. Perhaps some pilot programs to expand MDE collection to include treatment.
5. Develop a repository of program research outcomes.
6. Seek new strategies for potentially new demographics of women.
7. Be more proactive in getting vaccinations to daughters of women who have not been screened.
8. Get lots of people vaccinated with HPV. This would involve lots of education to women (long-term goal).
9. Determine where men/boys fit in this and how they can support women. Even educational outreach to men about male breast cancer.
10. Within health care systems, have strategies to monitor performance in relation to targeting under-served populations.

## **Affordable Care Act**

1. Evaluate program impact looking at mortality of breast and cervical cancer among any woman in the program. Investigate possible comparisons (e.g. stage at diagnosis, etc)
2. Look at strategies to demonstrate, maintain program in light of ACA by designing studies to make the case of sustaining program and emphasizing organized screening (look at impact, effectiveness and efficiencies).
3. Package as formal policy analysis. Here is what it looks like if program is maintained or if it goes away.
4. Develop model for linking woman and insurance coverage as it becomes available. Consumer education tool or peer-to-peer education.
5. Evaluate/implement alternative payment systems to ensure timely and quality diagnosis and treatment,
6. Develop and evaluate strategies for engagement of populations at risk due to lack of access (e.g., new immigrants) like using community health workers.
7. Investigate potential for public/private partnerships to achieve the goal of population-level cancer prevention.
8. Funneling ACA through NBCCEDP and using the existing infrastructure. Continue using provisions through B&C program (possible example of public/private partnerships).
9. Consider flexibility to enable focus on women at highest risk.
10. The 60/40 flexibility should be allowed with use of waivers. Allow provision for greater flexibility based on CDC's assessment of program (e.g., include patient navigation in the 60%.)
11. Use CMS innovations to inform possible program changes.
12. Re-evaluate items included in performance-based budgeting.
13. Maintain women's functional access through NBCCEDP.

**BREAST AND CERVICAL CANCER EARLY DETECTION AND CONTROL ADVISORY  
COMMITTEE MEETING  
AGENDA  
December 6-7, 2012**

**Centers for Disease Control and Prevention  
University Office Park Campus, Columbia Building  
Atlanta, Georgia**

**MEETING OBJECTIVES:**

- Committee members are charged with advising the Secretary of the Department of Health and Human Services (DHHS) and the Director of the Centers for Disease Control and Prevention (CDC) regarding the early detection and control of breast and cervical cancer.
- Committee members will discuss and make recommendations regarding national program goals and objectives; implementation strategies; and program priorities.

**Day 1: Thursday, December 6, 2012, Room 1065, 9:00 A.M. - 5:00 P.M. ET**

Time	Event	Speaker
9:00 A.M. - 9:10 A.M.	Opening Welcome	Jewel Mullen Jameka Blackmon (CDC)
9: 10 A.M. - 10:10 A.M.	Advisory Committee Role and Responsibility	MASO (CDC)
10:10 A.M. - 10:30 A.M.	Member Introductions	Jewel Mullen
10:30 A.M. - 10:45 A.M.	BREAK	
10:45 A.M. - 11:00 A.M.	Division of Cancer Prevention and Control Update	Marcus Plescia (CDC)
11:00 A.M. - 11:20 A.M.	Overview of the National Breast and Cervical Cancer Early Detection Program	George-Ann Townsend (CDC) Jerry Cook (CDC) Felicia Solomon (CDC) Janet Royalty (CDC) Quanza Brooks-Griffin (CDC)

11:20 A.M. - 11:30 P.M.	Q&A	
11:30 A.M. - 12:30 P.M.	Discussion # 1: How to approach health systems change Presentation: What CDC is currently doing	Jewel Mullen Faye Wong (CDC)
12:30 P.M. - 1:30 P.M.	LUNCH	
1:30 P.M. - 2:30 P.M.	Discussion #2: Enhancing population-based screening through monitoring Presentation: Performance management	Jewel Mullen Amy DeGross (CDC)
2:30 P.M. - 3:30 P.M.	Discussion #3: Approaches to decreasing disparities Presentation: Breast cancer mortality disparities	Jewel Mullen Jacqueline Miller (CDC)
3:30 P.M. - 3:45 P.M.	BREAK	
3:45 P.M. - 4:30 P.M.	Key recommendations to CDC	Jewel Mullen
4:30 P.M. - 5:00 P.M.	Wrap-up! Announcements Adjourn	Jewel Mullen Jameka Blackmon (CDC)
6:30 P.M.	Optional Dinner	Marlowe's Tavern

**BREAST AND CERVICAL CANCER EARLY DETECTION AND CONTROL  
ADVISORY COMMITTEE MEETING  
AGENDA  
December 6-7, 2012**

**Centers for Disease Control and Prevention University Office Park Campus  
Columbia Building  
Atlanta, Georgia**

**Day 2: Friday, December 7, 2012, Room 1064, 9:00 A.M. - 11:30 P.M. ET**

Time	Event	Speaker
9:00 A.M. - 9: 15 A.M.	Highlights and Review	Jewel Mullen
9: 15 A.M. - 10:45 A.M.	Discussion #4:  NBCCEDP changes as Affordable Care Act is implemented across states and identifying a public health niche  Presentation: Public health niche	Jewel Mullen   Mike Mizelle (CDC)
10:45 A.M. - 10:30 A.M.	Questions and comments from the public	Jewel Mullen
10:30 A.M. - 11:00 A.M.	Review of recommendation/ Identify next steps	Jewel Mullen
11:00 A.M. - 11:30 A.M.	Wrap up/Announcements  Adjourn	Jewel Mullen  Jameka Blackmon (CDC)

**Department of Health and Human Services  
Centers for Disease Control and Prevention**

**Breast and Cervical Cancer Early Detection and Control Advisory Committee  
December 2012**

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