

Office of Disease Prevention and Health Promotion
Healthy People 2020 Progress Review
Cancer & Genomics, February 6, 2013, 12:00 p.m. ET

HOWARD KOH: The Progress Review process is one that we're very proud of and people who have been part of other iterations understand this process well. Today, what we're going to do is start in on the first Progress Review on these two key Topic Areas, Cancer and Genomics.

We're going to show everybody some data, updating progress on these key Healthy People 2020 objectives and then, most importantly of all, have some discussion, led by a number of great experts in this room, about what's being done and how we can do even more. Next slide, please.

This is a fascinating slide, the evolution of Healthy People and what is so thrilling for me, as the Assistant Secretary, is to help oversee a process that's going into its fourth decade. If you just track the goals, the number of Topic Areas, the number of objectives and measures, this has grown dramatically since it was first started for Healthy People 1990. So here for Healthy People 2020 we have some 42 Topic Areas. We have over a thousand objectives and measures, but the good news is that we're being flexible in this day and age and putting a lot of this information online to have it within reach for people and to really make Healthy People come alive. Next slide, please.

So here are some resources for you. We have healthypeople.gov, by the way. If you haven't visited that site, please do so. I want to acknowledge the incredible colleagues at the Office of Disease Prevention and Health Promotion. I want to acknowledge the great leadership of Dr. Don Wright and Carter Blakey. Where is Carter today? I can't believe that. Oh no. Carter is so dedicated to this. We are very proud that, because of these efforts, we are reaching more people with this initiative. It's a source for reliable, science-based public health measures. It can be customized to diverse users and it drives collaboration in ways that are really extraordinary. We're very, very proud of that. Next slide.

So, as I mentioned, because there are 42 Topic Areas, we are starting this Progress Review process where we're going to meet every several months and review two Topics at a time. Today, we're starting off with Cancer and Genomics for obvious reasons. This is a huge public health challenge. Cancer is the second leading cause of death in the country. Some 12 and a half million Americans have had a cancer diagnosis. Many billions of dollars in costs. We're in an era where early detection can be enhanced by attention to genetic testing and counseling, such as that recommended by the U.S. Preventive Services Task Force. So, that's what we're going to do today. My last slide before I turn it over is just reviewing the remarkable experts who are going to be presenting in today's Progress Review. I am so grateful to Dr. Ed Sondik from the National Center for Health Statistics. He is an absolutely passionate leader in health statistics in general and Healthy People in particular. You're going to hear from Dr. Sondik in just a couple of minutes on some of these key data points. Then we're going to be hearing from two wonderful leaders in cancer and public health, Dr. Bob Croyle from NCI and Dr. Marcus Plescia from CDC.

In the genomic area, we have Dr. Muin Khoury from CDC and Dr. Carolyn Clancy is on her way. She is Director of the Agency for Healthcare Research and Quality. And then, very importantly, we're having a community perspective because we want to honor the heroes out in the field who are doing this work and making Healthy People come alive.

ED SONDIK: I think we all have a sense of the impact of cancer, but I think when you look at the statistics, they really are stark. It's the second leading cause of death in the U.S. after heart disease. Actually, when we look at the data for 2012, it will probably be the leading cause as soon as that data is in. The cost is staggering, over 200 billion dollars a year for all cancers combined. We know that we can impact this and, in fact, the objectives that we're going to focus on today, objectives related to breast cancer and colorectal cancer, emphasize that early diagnosis and screening can reduce mortality. I think the starkest figure for me, the strongest one, is that two in five of us will have a cancer diagnosis during our lifetime and about one in five of us will actually die from cancer. At times, we think of cancer as a rare disease, and sometimes epidemiologically it is, but in fact it's not. It's something that affects all of us.

On the next slide is a summary of the cancer deaths. Everyone can download the slides or some of you have them ahead of time. Let me just point out that, actually, four cancers make up over 50 percent of cancer deaths for both men and women. That's lung cancer, the lymphomas, colorectal cancer, and pancreatic cancer. And to that, if we add another couple of cancers for males and females, we get up to over 70 percent when we add breast cancer to the mix, ovarian cancer, prostate cancer, and also in males, liver cancer is also particularly high.

On the next slide we turn to genomics. We know that genetics can play a role. This is a new Topic Area for 2020. It can play a role in nine of the ten leading causes of death. These are outlined in the slide. Here, we're focusing on cancer in particular. For those who are at increased risk for hereditary breast and ovarian cancer and colorectal cancer, genetic tests can enable early detection and reduced mortality.

The next slide just summarizes what we're going to focus on today. Again, it's breast cancer and colorectal cancer and then a single objective of the two in genomics having to do with breast and ovarian cancer. So let's go to the data, as they say.

Our slide number seven is colorectal cancer deaths. We've actually made over the last decade considerable progress here, falling from almost a rate of about 21 per hundred thousand down to about 16 per hundred thousand, which, relatively speaking is a decline of about 24 percent. So, that's quite positive.

This slide is broken out by race and ethnicity and what I call your attention to... I think the most salient feature on this, in addition to the decline, is the fact that the black rate is 43 percent higher than the white rate. Now it turns out that, just because of the numbers here... that the way it works out...that the total is the same as the white rate, approximately the same. So when we graph it, one is essentially on top of the other, and that just turns out...that has to do with the rates, the size of the populations, and so forth. The target is based on...this is true for all of these... the target is based on what the rate was for the total in 2007 and the target is ten percent less than that. I am really loath to say...probably not my role as the data person... but I really am loath to say that the races and ethnicity that lie below the target have actually met the target. In fact, what we'd like to see is progress over the decade...we're very early in the decade, obviously... but progress over the decade on all of these and, of course, combining them all together to meet that target figure.

The next slide is breast cancer deaths. It looks very, very similar. Here again, the most salient...the two salient features are that there has been a decline, not as much in the breast cancer rate as there was in

the colon cancer rate, but the disparity between the white rate and the black rate is, again, over 40 percent, about 41 percent in this case.

The next slide takes the breast cancer data and graphs it according to some modified health service areas. In large part, this reflects the prior slide. It reflects where people, particular races tend to live. But it's not all that. There are other clues and cues in here that are very important to investigate. We just show this slide, not because it's a specific objective, but because it says there are many different ways to look at the data.

There is an interesting point on this and I won't go into it, but if you go to the very top of North Dakota, it turns out that there is a very high rate. We don't know whether that rate is due to small numbers, a small denominator, so to speak, population where each case can make a significant difference. Frankly, if these rates were not five-year rates and three-year rates, it wouldn't show up. But again, it gives clues as to where we might go. That's actually just to the northeast of Minot. I think it's called Pierre, North Dakota. I bring it up because you really do need, when you look at something like this, to investigate and understand the nature of the data.

Now, turning to incidence on the next slide... it's a slide showing the new cases of colorectal cancer, the objective for that, with the target, you can see, somewhat below the 2009 rate, really ten percent below the 2007 rate. Significant progress here in reducing the number of new cases of invasive colorectal cancer. In fact, this is a decline over the decade of about 25 percent. The disparity, 'though, the one that I would focus on, the disparity between the black rate and the white rate persists here, but also we see a significant disparity here between the male rate... rate for males and females.

Turning in the next slide to late stage female breast cancer, we see that there's been a decline over the decade, a much lower decline, in the number of new cases. This was a decline of four percent between 1999 and 2009, the two bars on the on the left. Again, the disparity persists, with the black rate well above the target set on the overall total rate, the white rate very close to that target.

On the next slide, we turn to the third part, I guess you could say, of looking at cancer. We looked at deaths, we looked at incidence, and now we look at screening. Looking at screening... the target... what we want here is the percent who have had screening according to the guidelines. We want that to increase and, if we look at the figures from 2008 to 2010, in fact, screening meeting the guidelines for colorectal cancer went up 14 percent. I think that's actually a very impressive rise over a short period of time. I call your attention to the race and ethnicity side and the income side. See the disparities. I think it's fairly stark, these disparities. But keep that in mind, though, when we go to the next slide and we look at screening for breast cancer. It's interesting here that the disparity in income basically persists, except for the very lowest income figure, which is higher than one would expect based on the colorectal figure. Interestingly enough, we don't see the same distribution of disparities by race. In fact, the black, the white, and the Hispanic rates are all very, very similar

Turning next to... on the next slide to genetics, the objective here has to do with women who have a family history of breast cancer and ovarian cancer. In this diagram, the pie chart shows that this is about five percent of women. Next slide.

We can see that, in terms of point estimates, we've gone from about 33 or 34 percent of women who've discussed genetic testing... women with a family history who discussed genetic testing, up to something over 50 percent. Well this is very positive, but...and there's a significant but here... the but is

that the numbers here give rise to some very large confidence intervals. While you'll see in our charts it says that we have met the target, I would not put that in the bank and take it home. We need to see what happens with this over time. I think the point estimates are always encouraging, but sometimes I think we get too much encouragement just from the point estimates because, as some wise statistician once said, two points don't make a trend. Alright, you can quote me on that one. I'm not the wise one, though.

On the next slide...just a summary of the cancer objectives. I want to call your attention here to the fact that we've dealt with six of them here, but there's a total of 27 cancer objectives. As you'll see in the slide I'll go to in just a second, we see over this very short period of time to evaluate, we're doing well, but it's important to point out, for example, that melanoma deaths has a red dot on it. It's not going in the right direction, although it's moved a very, very, very small amount. So, in order to discuss that, we need to know something about screening and other interventions.

To go to the next slide--this summarizes the 27 cancer objectives. The greens are all movement – either target met or movement in the right direction. The yellow is no change. Then there were four objectives that moved in the wrong direction, albeit maybe a very small amount of movement, given that we're only evaluating the difference between around 2009, or maybe a little bit earlier than that, and the current time. And there are eight objectives for which we either have only baseline data or developmental data.

The next slide turns to genomics, and we have two objectives here. I think I've already discussed that chart with the two bars. While it's green on here, as I said, I'm not sure that we have won that objective... at this early point, that it has met the target. I think we need to see more. The next one, in terms of a measure or data to help us detect or evaluate the percentage of people being tested for colorectal cancer with Lynch syndrome, we need data for that.

So, to summarize, which I can do very briefly... We clearly over the past decade... there's without a doubt been progress in reducing death and incidence rates for the major cancers, the cancers we're focused on here, colorectal cancer and breast cancer. The disparities, though, I think are stark and persistent. There's particularly the disparity between whites...between the white rates and the black rates. We continue to have even with...as of late, even larger surveys. We have a challenge in collecting data from the smaller populations. We also have something that we haven't had before, in the third bullet, which is that screening guidelines are changing more rapidly than they did in the past, which poses a challenge in just tracking how well we're doing. It's entirely feasible, but it is a bit of a challenge. And again, in the genomic objectives, particularly the one that we're looking at, we're challenged here by the relatively small target population and the fact that we'd love to see a much larger survey that could give us more figures.

HOWARD KOH: Let's move on to two cancer leaders who are going to comment on successes and challenges they see from these data. The first is our wonderful colleague, Dr. Bob Croyle, who is the Director of the Division of Cancer Control and Population Sciences at the National Cancer Institute. So, Dr. Croyle has eight minutes.

BOB CROYLE: Thanks, Dr. Koh. So, my purpose for this group today is to give you a few illustrations of the kind of research that the Cancer Institute, along with our partners in HHS are currently funding, to inform all of you in terms of cancer control strategies, with a particular emphasis on these two

domains of colorectal cancer and breast cancer. So, to go to the first slide. This lists some of the areas of research emphasis for a component of the NCI which focuses on cancer control and population science. Overall, one of the messages, take-home messages I want to leave you with is that the type of research that NCI has been funding and Cancer Control has been changing over the last few years, with a greater emphasis on the cancer control domain of research that's pragmatic, that's relevant to you, and that is collaborative with CDC, AHRQ, and our other federal partners. So, these topic areas are illustrative of research on screening, of course. Many of you are familiar with screening strategies. Also, these related research areas...health disparities, as Dr. Sondik mentioned... more healthcare research, along with the Agency for Healthcare Research and Quality, NCI, and the rest of the NIH have been more engaged in healthcare-related research these last few years. Research in health communication... this has been quite a focus for us in NCI these last few years. More studies of how to communicate, monitoring of communication, and health literacy, in particular. Decision making, particularly in those domains where we don't have definitive evidence. And we need good patient-provider communication. Then, also the development of better measures, both for surveillance and implementation science.

The next slide illustrates how we're thinking of screening from a research and practice perspective, not just in terms of, is someone screened or not, but as many of you who work in the field know, looking at screening as a process. This is important, because each of these components of screening as a continuum, as an entire process, needs to be informed by research, not simply guidelines about breast cancer screening or colon cancer screening, but also evidence to inform strategies, follow-up, making sure that communication is effective, and that we're having the greatest positive impact on health outcomes.

So, the right part of the slide illustrates kind of the breadth of areas that we're really funding in research these days and patient outcomes, more not only on biological outcomes, but quality of life as an outcome and also the patient experience, whether it's financial impact, psycho-social impact, impact on families. This also requires research that...it involves more patient engagement. Next slide.

So, one example of a recently funded initiative, funded by the NCI, that we developed with a lot of input from our colleagues at CDC, is the PROSPR initiative. This was built on a previous initiative we funded for years, the Breast Cancer Surveillance Consortium, which focused exclusively on mammography. PROSPR expands that effort to other screening domains breast, colon, and cervical. We're also exploring the possibility of ramping up additional research to look at the implementation of lung cancer screening in future years. So this research network is a collaborative research network, a group that monitors and evaluates implementation of screening, again, focusing on the entire screening process, not just on whether somebody gets a screen or not. The objectives are illustrated there. This is something we're quite excited about because we know from previous experience in the domain of mammography that we need very high quality data on the implementation, and the quality, and the performance of screening across the country. Next slide.

Another example is a trans-NIH effort, of which NCI is just one component, but again, it illustrates some recent efforts to expand NIH research efforts that fill the gap between the mission domains across CDC, NIH and AHRQ. This is the Health Care Systems Research Collaboratory. This is funded centrally. It's what we call a common fund initiative involving many Institutes at NIH, funded by the NIH Director's Office.

One of the projects that we manage is one focused on implementation of colorectal cancer screening. This Collaboratory is, again, an effort to bridge traditional NIH-funded research, oftentimes conducted within academia, with research conducted within healthcare systems. Next slide. So, that's one example. This just illustrates the types of research we're funding through this new effort, this trans-NIH effort, funded by Gloria Coronado, and it's working at a number of different types of healthcare settings, different kinds of clinic settings, focusing on underserved populations, particularly the FQHCs, the Federally Qualified Health Centers, and looking at ways to increase colorectal cancer screening by working with healthcare systems to implement monitoring, evaluation, and follow-up and tracking within the electronic health record. Next slide.

Also, what I wanted to mention to you, which often is less familiar to many of you in the community, is our expanded efforts in modeling, that is, statistical modeling to understand incidence, mortality, and risk factor trends at the population level. So, in the cancer domain, our signature effort is the Cancer Intervention and Surveillance Modeling Network. I won't go through this in any detail, but you can google this. There is a lot of information on our website. We're using this to synthesize and integrate data from a whole variety of surveillance sources and then generate projections and models that can then be used by policymakers and also inform the Preventive Services Task Force on what are the most effective strategies in cancer control. Next slide.

I also wanted to highlight our work with the HMO Cancer Research Network. The Cancer Research Network, as indicated on this slide, involves a consortium of integrated managed care organizations. This is a good example of utilizing healthcare systems, particularly integrated networks, as platforms for larger scale research in cancer control. So, we're really looking for more team science, more collaborative science, more research conducted within the healthcare system, again, in collaboration with key partners like AHRQ and CDC. Next slide.

Also, I wanted to give some examples of the broader way that we're thinking of cancer surveillance and cancer surveillance relevant to cancer control. So, in addition to the traditional domains of incidence and mortality and behavioral risk factors, we've been scaling up a number of surveys, surveys of physicians, for example. This second bullet on this slide, the Health Information National Trends Survey...again, a lot more information on our website. You can google HINTS and find that. This, for example, is a way to think broadly of how we monitor, in this case, the public's knowledge, awareness, and risk perceptions related to cancer and then also track information about how people get cancer information, their use of the Internet, what sources of information they rely on, because our sources of information have become more diverse and more complex with expansion of the Web.

Finally, on this next slide, I wanted to make sure that many of you are aware...I know that some of you are...about the cancer control PLANET portal. This is a collaborative web portal that involves not only our HHS partners, but also NGOs like the American Cancer Society. This is intended to be kind of a one-stop shop to pull together lots of surveillance data, our research and intervention programs, evidence synthesis reviews, a whole variety of resources.

So, I know many of you are familiar with the cancer control plans, but if not, I really encourage you to visit this. The purpose of this is to make a lot of the data and resources from all of our agencies and partners readily accessible and usable to all of you.

MARCUS PLESCIA: What I'd like to touch on in this presentation today is some discussion of some of the evidence-based strategies that we try to use to increase breast, cervical, and colorectal cancer

screening; ways we integrate cancer screening with other publicly-funded health programs; how we apply relevant research to local cancer prevention control needs; and how we partner with other federal agencies.

As you see from this slide, CDC actually administers four national programs and three of those are highlighted on this slide. Those are the three I'll talk about today. Let's give a little bit of background, though. The majority of the funding that we provide at CDC is provided to health departments. We fund states, Tribes, and territories to apply scientific advances in the community to develop strong cancer prevention and control programs. We do this by working in four different domains and these are not listed on the slide, but I did want to run through these quickly because I think it gives a little bit of perspective of how CDC does its work and, particularly, how state health departments do their work.

The first area we try to work in is around epidemiology and surveillance and we try to use that as the basis for which we set priorities and define our work. The second area is around environmental approaches. These are essentially policy changes that are put into place in various settings that are designed, as we like to say, to help make the healthy choice the easy choice.

The third area we work in is health systems interventions. These are interventions to promote health and support and reinforce... I'm sorry; these are interventions to improve the delivery of clinical and other preventive services. The final area we work in at CDC is community clinical linkages. These are linkages that allow us to increase support for self-management of chronic conditions. So, a good example of that is some of the work we do around working with cancer survivors in trying to link cancer survivors in the clinical community to the community resources that they need. Ultimately, we aim to translate research, like the work that doctor Croyle just spoke about, into public health Practice.

CDC supports a wide variety of programs, initiatives, and campaigns and has an extensive public health research portfolio. I'm not going to be able to speak about all of these today, but this slide is put here to just give you a sense of some of the wide variety of activities our Division supports. So, one program that I'd like to highlight, which I think has a direct influence on meeting the Healthy People objectives is CDC's National Breast and Cervical Cancer Early Detection Program. This program currently provides low-income uninsured and underserved women access to timely breast and cervical cancer screening and diagnostic services. We've been operating this program for two decades and, in that time; we've developed significant capacity in state health departments to provide public health approaches to cancer screening and to offer screening services. We're very, very proud of the success of these programs. We actually think that they've had perhaps something to do with some of the parity in screening that Dr. Sondik mentioned earlier amongst various racial and ethnic groups.

Since 1991, the program has provided more than ten million breast and cervical cancer screening examinations. In the program, we've diagnosed more than 55,000 breast cancers and more than 3,000 invasive cervical cancers. Also, in addition to screening, the program allows all 50 states to use a Medicare...I'm sorry, a Medicaid coverage option that allows and provides treatment to women screened positive through the breast and cervical cancer program so they can then go on and receive the very important diagnostic and treatment services that they need.

Now, this slide is very important to us at CDC because it gets a little bit into what we see as some of the future roles of public health in cancer screening and some of the objectives that we really...some of the approaches that we really think will help us meet these objectives.

We believe that implementation of the Affordable Care Act will clearly benefit the populations that we traditionally serve through this program. The Act will increase insurance coverage and it will require coverage for breast, cervical, and colorectal cancer screening without cost sharing. So, we think that, with full implementation of the Act, we'll see significant benefits to the population we serve as far as screening numbers.

Ultimately, what we see here is an opportunity to really build on the existing capacity we've put into place in state health departments and some of the extensive clinical networks so that we can develop some new approaches to increase participation in cancer screening. These are population-based approaches that we think are particularly important in enhancing participation for underserved populations and they're captured here in this slide. These approaches include public education, care coordination, quality assurance, surveillance and monitoring, and development of highly organized screening systems. We believe it's these kinds of approaches that will build on the benefits of the Affordable Care Act and will help us contribute significantly to reaching the objectives of Healthy People 2020.

This slide is an overview of our most recent screening program, the Colorectal Cancer Control Program, which is our newest addition to our portfolio of screening services. This program has been organized in a slightly different way in keeping with some of the objectives I talked about in the last slide. We created this program in 2009 and it was put into place with a distinct emphasis on promoting population-based approaches to colorectal cancer screening, so we require our grantees to use a least two-thirds of their funding to take these kinds of population-based approaches and then we allow them to use about a third of the funding to actually pay for clinical services.

Given the low rates of screening participation, even in currently insured populations, we believe that this kind of population-based approach will really contribute significantly to helping us increase rates of participation in colorectal cancer screening and ultimately in meeting the objectives of 2020.

I wanted to hit briefly on a couple of innovative approaches we've tried to foster at CDC and this is really along the line of trying to develop more organized approaches to cancer screening that I mentioned as one of the main areas of emphasis as we move forward. I'd like to highlight two programs we fund. The first is in Minnesota. The Minnesota Department of Health is collaborating with their state Medicaid program, through funding from CDC, to increase screening among the state's unscreened Medicaid beneficiaries. They're doing this by using direct mail reminders and then, in kind of an interesting twist, by using modest financial incentives to get people to participate from the Medicaid population. Another example is the New York State Department of Health.

The New York State Health Department is partnering with a group of Federally Qualified Health Centers across the state to develop screening registries, so they're in each of the Federally Qualified Health Centers. They can actually track the patients in their practice that have been in for screening versus the patients that are actually eligible to be screened and then take measures to try to bring those people in if they're not participating. We think these kinds of really highly organized approaches are the types of things that will help us meet the objectives of Healthy People 2020 and really bump up screening rates, particularly for breast and cervical cancer screening, where our Participation is already quite robust. So, we need some of these more organized approaches if we want to reach even further into those populations.

I would like to briefly talk about some of the work that we do with federal partners, particularly at the National Cancer Institute, to meet the Healthy People 2020 objectives. A very good example of this is our collaboration together with NCI to work on the Cancer Prevention and Control Research Network. This is a network of community-based participatory cancer research centers that are situated across ten academic centers. This network provides a very important infrastructure for us to apply relevant research to local cancer prevention and control needs. The Network aims to provide expertise for research supporting...provide more evidence-based approaches that we can use to further define the areas available for population-based interventions that we seek from the Guide to Community Preventive Services.

This is just a quick example from Washington University of the kind of work that these research networks do. This is a study that Washington University did, tapping into the work of United Way's 2-1-1 call system. This is a system that people can call into for help with a variety of needs for essential services, like food and shelter. What Washington University did was tie in a component to try to help people gain better access to screening services. As you see from the slide, we saw significant improvements when this line was used together with follow-up, verbal referrals and follow-up from a patient navigator. Next slide.

So, I'd like to close by discussing something that we think is one of the most important factors in tracking our progress in meeting the Healthy People 2020 objectives. This is having good data to track our progress. The Centers for Disease Control and the National Cancer Institute collaborate to produce cancer incidence data for the entire Nation. The National Cancer Institute supports the Surveillance, Epidemiology, and End Results program, also known as SEER, which funds cancer registries in ten states, six metropolitan areas, and the Alaska Native Tumor Registry. Then, CDC supports the National Program of Cancer Registries, which basically supports cancer registries in the remaining states. Through these two registry programs, which we do a very good job of collaborating to combine, we are able to really produce a census of all of the cancer cases across the United States. This allows us to track our progress with the Healthy People 2020 objectives, but it also allows us to do extremely important work around looking at the reach and quality of cancer services across the Nation.

MUIN KHOURY: What we're trying to do here is to try to identify more than a million people in the United States who are at risk for certain types of hereditary breast, ovarian, and colorectal cancer and would benefit from evidence-based preventive interventions. Next slide, please.

So, our office...some background information...which is the latest kid on the public health block, so to speak. The whole field of public health genomics is a new endeavor trying to work effectively and actively to promote an integration of this new knowledge into public health programs to improve population health. What we do is... we have three goals. One is to implement evidence-based genomic testing and family history applications into programs. The second goal is evaluating the promising applications to provide new opportunities for integration into health care and public health. And the third is developing communications, publications, training, policy, and technical assistance to programs to meet those goals. Next slide, please.

As you can see, this is a screenshot from our home page. The year 2012 was sort of a good year for us because we celebrated 15 years of public health genomics in the United States. As you can see, we deal with so many things other than cancer, from infectious disease to chronic disease, maternal and child health issues. It's just that a lot of the action that's ready for application right now happens to be in the cancer field. Next slide.

So, recently our office has created...developed a framework, an evidence-based framework that uses sort of evidence cobbled from everywhere to classify genomic tests and family history applications based on the availability of scientific evidence, as well as the evidence of basic recommendations supporting their use. You can see that there is a website there. I invite people to go through it. There is a database that can also be searched. The applications there are those that are ready for prime time, so to speak, have evidence-based recommendations supporting their use. There are quite a few in that tier one already. A few applications that are somewhat on their way and could be useful for informed decision making based on demonstrated clinical validity and utility and promising utility, while two or three belong for the most part in the research realm, where the evidence of utility hasn't been there yet, but they are candidates for clinical and population research. So, tier one applications obviously include the two recommendations we have for Healthy People 2020. So, next slide, please.

This is a reiteration of the two genomic objectives for 2020. Dr. Clancy will be discussing the first one, which is based on the AHRQ-sponsored U.S. Genomics Services Task Force. The second objective, which is based on a 2009 recommendation from the EGAPP working group...I'll tell you more about that in just a minute... but the second one reads that what we're trying to do is, "Increase the proportion of persons with newly diagnosed colorectal cancer who receive genetic testing to identify cases of Lynch syndrome."

So, these are not the only genomic objectives in Healthy People 2020. There are other objectives, like newborn screening, hearing loss, and some from the Blood Disorders Topic Area, which we are not covering today.

So, next slide. I'll just give you a feel of the EGAPP working group. The EGAPP working group has very much been modeled after existing efforts, like the U.S. Preventive Services Task Force. It's the only group in the world that actually takes on genomic applications for health care and public health. It's been active. It's an independent, non-federal, multidisciplinary panel. It has a steering committee from several federal agencies. They have been working on developing, in an area that is rapidly moving, systematic methods for evaluating validity and utility of genomic applications and tests and then developing new methods for evaluating that information, including a recent...anticipating the arrival of the next generation of whole genome sequencing and stratified screening, which are both anticipated in the next couple of years. They've already published six recommendation statements to date on diverse topics, from cancer to other areas, on heart disease, on clotting disorders, on depression. There are upcoming recommendations this year on prostate cancer, diabetes, and other topics. Next slide, please.

So, over the last few years, we've supported a number of implementation research programs, including healthcare systems and a project we have with the VA in southern California, but I'd like to highlight some of the state-based activities. Basically, we've funded states for the last few years to identify people targeted by the Healthy People 2020 objectives using cancer registries educating health providers about evidence-based recommendations, as well as implementing model policy for payers to facilitate the coverage that's consistent with our breast and ovarian cancer objectives and now covered under the Affordable Care Act and developing and evaluating new data sources to measure progress towards these objectives. Next slide, please.

So, one of the things that the states are doing is they are using cancer registries that Marcus mentioned earlier, bi-directional reporting to identify the cancer cases that are relevant to the Healthy

People 2020 objectives that are reported to the cancer registry. The states now are beginning to inform reporting institutions of the relevant cancer cases and provide information materials about hereditary breast and ovarian cancer, as well as Lynch syndrome. For example, the Michigan Department of Community Health has reported back over 15,000 cases of cancer relevant to Healthy People 2020 objectives based on 2007 and 2008 data. This work is now beginning to be expanded to other states, such as Connecticut, which has now reported back over 5,000 cases of cancer based on 2008-2009 data through the Healthy People 2020 Action Award, which they got. Next slide.

In this slide, we show that, in the policy realm, there is quite a bit of activity. For example, the Michigan Department of Community Health has partnered with major payers to implement payer policies consistent with the U.S. Preventive Services Task Force recommendations and the Healthy People 2020 cancer objectives. So, from 2008 to 2011 insurance coverage consistent with those recommendations has been extended to 6.6 million Michiganders. We also partnered with the Division of Cancer Prevention and Control, who are examining medical policies related to genetic counseling for hereditary breast and ovarian cancer across the Nation. So, of 348 health plans across 38 states, 58 percent of them currently have written policies about that. Next slide.

So, coming soon to our website are two things. One is a clickable map of state activities relevant to public health genomics that would include these two Healthy People 2020 objectives and, over time, will include many other applications, and a new toolkit that would be available to all states and programs and communities to begin to implement public health genomics programs, at least the ones that are consistent with the tier one application. Next slide

Although there is no time to discuss it in any detail, it is very important to mention at this point... and maybe we will have more discussion... that there are a number of federal initiatives and policies that can actually contribute to progress towards Healthy People 2020 objectives in cancer... in genomics. The first one is the Affordable Care Act that covers now the U.S. Preventive Services Task Force Recommendation on BRCA1. Counseling and testing...that's the G-1 objective. Family health history. Meaningful use of electronic health records will be a facilitator in implementation because the hereditary breast and ovarian cancer objective relies on family health history, as Ed Sondik showed you the data from the national perspective.

Similarly, the inclusion of family health history in a public health reporting initiative could be a facilitator. There are also new CPT codes for molecular diagnostics, which will be implemented starting in 2013, which could facilitate the tracking of genetic testing and practice. Next slide, please.

So, before we get too far ahead of ourselves, we have many challenges ahead in this new area. Genomic medicine is obviously an up-and-coming field and the promise is great. The problem is that the evidence of utility has been slow to accumulate, while there is still plenty of work to do in the basic science and discovery. Providers are not aware even of evidence-based guidelines and recommendations. They need a lot of awareness education. The need for genetic and genomic professionals is great. The healthcare system as designed right now has its own limitations and absorbing this new era of genomic and personalized medicine is a challenge. There are obviously many lab issues for implementation from quality assurance to reporting and all those things. And a whole slew of ethical, legal, and social issues, which we can discuss. Coverage and reimbursement is always key. Like in new areas and technologies, there is always the potential for increasing health disparities in the population.

CAROLYN CLANCY: So, just a little bit of background on AHRQ and what our role is in helping to advance these objectives. Our mission is to improve the quality, safety, efficiency, and effectiveness of health care for all Americans and we do that by supporting research that helps people make more informed decisions, for example, about cancer screening. It improves the quality of those services. We also work to translate that knowledge into guidelines, tools, and so forth that people can use to improve safety and quality. Most of our work is done through grants and contracts. Next.

Now, many of you are familiar with the U.S. Preventive Services Task Force. This is an independent group of national experts in prevention and evidence-based medicine. I believe it is close to thirty years old. It was originally started by the Office of the Assistant Secretary for Health, moved to AHRQ in 1995; it's an independent group of national experts in prevention and evidence-based medicine, and they develop recommendations on clinical preventive services, such as screening, counseling services, and the use of preventive medicine. By law, AHRQ convenes the Task Force and provide scientific and administrative support of its operations. Next slide.

So, the Task Force itself systematically reviews evidence for clinical preventive services implemented in a primary care setting. By and large, the Task Force is addressing whether this is recommended for people walking in, not with a specific complaint or specific risk factor, but just all comers. These recommendations are intended to help primary care clinicians and patients decide together whether a preventive service is right for that individual's needs. If you want to learn more, they have their own website, a very big mouthful uspreventiveservicestaskforce.org. I believe it's case insensitive, but they are easy to find. Next.

Now, the Task Force's recommendations are important to many of the objectives in Healthy People 2020 relevant to our review today. They've made several recommendations for screening, counseling, and preventive medications to reduce cancer rates or to help identify cancer earlier. Two of their recommendations are listed on this slide, screening for cervical cancer and counseling young people to reduce their exposure to UV radiation. Just a brief note about the cervical cancer recommendation.. significant, because the Task Force, which has an ongoing commitment to update their recommendations at least every five years, sometimes more frequently as new evidence emerges, actually did this in very close collaboration with both partners within HHS and partners in the broader healthcare community, the American Cancer Society, the American College of ObGyn, and so forth. This was the cervical cancer and at the bottom of the slide are just two of the Healthy People objectives supported by these recommendations. Next slide.

So, as Dr. Khoury mentioned, the Task Force's recommendation on genetic counseling for women with an increased risk, or BRCA1 or BRCA2, served as the foundation for the objective G-1, and their recommendation is seen on this slide and, notably, is currently being updated and it's being updated and this is a little salute to the Task Force and my colleagues who support their work... very consistent with the Task Force's new approach to transparency at all phases of the process. So, from the very moment that they decided to do an update, they convened stakeholders and got their input really at time zero. They got input on the key questions that would be addressed by the systematic review that we support. Then, the draft recommendation is out for public comment, and so forth. I don't believe it's out yet, but it will be. That's the new process. And I have to say that groups were very, very helpful with this recommendation.

Next. So, as a result of the Affordable Care Act, let me just say, everyone is extremely interested in the Preventive Services Task Force, because the A and B recommendations from the Task Force along with recommendations of three other groups ultimately guide Medicare, Medicaid, and private insurance

companies to increase access to clinical preventive services and to ensure that they are affordable, by which I mean, no co-payment for these recommended services. So, you can see that whatever reading it gets, gets a lot of attention. It particularly gets a lot of attention because the American public has very strong and generally extremely enthusiastic feelings about all preventive services.

We know from Medicare, for example, for preventive services to be covered used to literally require an act of Congress, sort of one at a time. Just because you're covered doesn't mean that people take advantage of the service. So, we have funded a variety of research activities to help implement the recommendations in other settings. So, for example, in our work...and we've been collaborating quite a bit with Dr. Koh's office on this... on improving care for people with multiple chronic conditions. Multiple studies have found that, if you've got multiple chronic conditions, often effective evidence-based screening kind of gets left off the agenda, partly because there are other issues to address and so forth. So our Center for Advancing Equity in Clinical Preventive Services at Northwestern University is developing and testing interventions to address that very gap and working very closely with FQHCs in the Chicago area. Next slide.

Now, tools for implementation...if it's just a recommendation in a journal article or on a shelf somewhere, it doesn't help very much. We still support the development of a clinical guide. It turns out clinicians like to have something to put in that proverbial white coat pocket, so we do that. We also have something I think is much snappier, which is an electronic preventive services selector, which you can do online or you can download a free app to your iPhone or other smartphone, and so forth. For a while, it was the leading free app for the iPhone. I definitely have to say something about myhealthfinder, where there's some terrific information for consumers about these recommendations, and there are also consumer fact sheets, and so forth. We work very closely and the Task Force, especially, works very closely with communications professionals to make sure that they're addressing the key issues of concern to the public. Next slide.

Finally, I just want to highlight a unique tool, originally developed by AHRQ, but now implemented by the CDC. We developed a computer-based clinical decision support tool to facilitate shared decision making between clinicians and women at risk of breast or ovarian cancer. The tool was developed to support the Task Force's recommendation on genetic counseling. CDC's Division for Cancer Prevention and Control picked up the concept and implemented it as BodyTalk. So, thank you to my colleagues from the CDC.

It has two interfaces: one is a patient portion of the tool, which was designed with the idea in mind that patients would actually think about this ahead of time before for their visit, allowing them to be fully informed about the conversation that's going to happen; the clinician interface allows that clinician to review the patient's history and provides resources for referring these high-risk women to the appropriate specialist. And the tool is really, I think, a very nice illustration of the kind of conversation that really needs to happen between patients and clinicians to make sure that patients get the most appropriate clinical preventive services for themselves and to make progress in increasing evidence-based screening in reducing cancer death rates.

SUMMER LEE COX: In the Oregon Genetics Program we strive to improve the health of all Oregonians and their families. We support evidence-based use of genetic and genomic applications and our mission is to promote the health, well-being, and quality of life for our population using genomic interventions and the public health model. Next slide, please.

One of our overarching goals is to safeguard the public from detrimental use of genomic information, while promoting applications where there is clear benefit. To do this, we use a three-pronged approach of surveillance, education, and policy. Our program collects population data that allows us to identify current gaps in knowledge and services and opportunities for change. This information helps us develop our strategies and create buy-in when we educate stakeholders about prevention, early identification, screening, treatment options, and referral for genetic services, which include genetic counseling and genetic testing. Next slide, please.

Having a BRCA mutation will greatly increase an individual's risk of developing breast, ovarian, and other BRCA-related cancers. Using genetic screening applications, such as the ones that Dr. Khoury mentioned during his talk, will save lives. Next slide, please.

In Oregon, we have almost three million adults, both males and females, in the population. We estimate that about 20,500 Oregonians are BRCA carriers and approximately 154,000 appropriate candidates will need to be tested in order to identify these carriers. Next slide.

In 2008, 840 Oregonians received genetic testing for BRCA gene mutations by Myriad, the only company in the U.S. that conducts this clinical test. In the middle bar, we see that less than half the BRCA tests were conducted in a facility where a trained genetic specialist was located. This may cause variation in the quality of genetic counseling and the decision-making process of the patient before and after testing. If we look at the third bar, we can see that the Medicaid population makes up just a fraction of those tested and highlights a large disparity. So, these multiple data sources tell us that we have a huge opportunity for screening through the use of genetic services and that some populations are currently experiencing noteworthy disparity. Next slide, please.

While our work largely addresses access to genetic services, it's important to note that cancer prevention, detection, and treatment involve multiple approaches that require a broad network of providers, agencies, and partners working together. I included just a few of our partners in this diagram to show how collaborations can affect one focus area or span into two or more areas. Our outreach into the Ashkenazi Jewish community, for example, allowed us to conduct educational activities within a targeted community, while our collaborations with Oregon Medicaid ultimately led to activities in all three of our focus areas. Next slide.

Surveillance is the foundation of our program. We have many data sources, including those listed here. Our program acts as a clearinghouse. After we gather the data from multiple sources, we analyze what each says to build a fuller picture of the situation and identify gaps in knowledge and services. Through this, we're able to use our data to directly support our policy and educational activities. Next slide, please.

We have three main educational goals and we tailor our messages to fit with the different populations we work with. Here, I'd like to focus on our recent work with the local Ashkenazi Jewish population. Last spring, we conducted an Ashkenazi Jewish BRCA awareness campaign, which included a four-hour training session with our staff, a local cancer geneticist, and a dozen Jewish women to increase their knowledge of BRCA mutations. We presented information about BRCA mutations and the implication for the Jewish community, given their increased risk of having a deleterious mutation due to ancestry. We reviewed the information packet we provided and engaged in a personal discussion of the impact of their experiences, shared stories, and gauged knowledge. Since then, attendees have formed their own workgroups to continue communications about BRCA throughout the Jewish community. We also

work with primary care providers, obgyns, cancer specialists, and other healthcare providers to support them in making appropriate referrals to genetics services. In 2010, we surveyed the top Oregon health insurance companies, private, public, and self-insured, and found inconsistencies in their policies for covering counseling, testing, and follow-up care. In the near future, we will be working more closely with health insurance companies in Oregon to ensure that Oregonians have consistent and quality care that they can depend on. Next slide, please.

We support the use of evidence-based recommendations, the appropriate use of genetic services, and the licensure genetic counselors. In 2011, we worked with Oregon's Medicaid program and Medicaid in Oregon now covers BRCA genetic services for those with and without cancer, matching current Evidence-based guidelines. We will study future Medicaid data to monitor the number of BRCA tests paid for and how quickly the socio-economic barrier to appropriate services may change. We will also be promoting the use of evidence-based guidelines, such as the National Comprehensive Cancer Network guidelines and the USPSTF recommendations, in our conversations with leading Oregon health insurance companies and healthcare providers. Next slide, please.

From these projects, we have learned that what gets measured gets done. Calculate your baseline data and use it to focus your activities. We use Healthy People 2020 targets when available to reassess our data over time. This helps identify gaps and unmet needs, as well. Multiple data sources are needed. Decisions are only as good as the data they're based on. Data from multiple sources can give you a more accurate understanding of the situation. For example, we used the data from the Oregon State Cancer Registry, Oregon Census, and the literature to estimate the incidence and prevalence of BRCA mutations in Oregon, as well as the number of adult Oregonians who may benefit from genetic services.

Multiple partners are needed, as well. From funding to creative thinking, including a diverse set of partners will help with limited resources. In addition, multiple and comprehensive approaches will get the job done. Solutions that are multi-pronged will more fully address the issues at hand. We work with patients, providers, and health insurance companies to promote the use of evidence-based guidelines in referring for genetic services. Next slide, please.

We will be working with the Oregon State Cancer Registry to send educational letters to cancer patients who may have a BRCA mutation and we will be sending these educational letters to the doctors simultaneously. We hope that this will increase the likelihood of genetic services being discussed during the next patient visit and provide them contacts for the discussion of referral. We will also discuss the tier one evidence-based genomic applications with health insurance companies. We will be sharing cost-effectiveness studies and emphasizing the potential for client support.

We will also continue collaborating with our many partners in the field of cancer, including the Oregon Partnership for Cancer Control, the Oregon Comprehensive Cancer Control Plan, the Breast and Cervical Cancer Program, the Oregon Cancer Registry, and many others. As I stated before, while our work focuses on increasing appropriate referral for genetic services, it's important to note that cancer prevention, detection, and treatment involves multiple approaches, including genetic services, and all approaches require a broad network of providers, agencies, and partners. Next slide.

Thank you so much for listening. Please feel free to contact any of us if you have questions about this presentation or our program.

HOWARD KOH: Let me start with the first one for Dr. Sondik. Dr. Sondik, could you comment on objectives related to cancer survival? You didn't present data on that, I'm sure because of the interest of time, but do you just want to make some comments on cancer survival?

ED SONDIK: Yes. Cancer survival has been rising, although slowly, but it's complicated by the fact that it's overall cancer. So, for some cancers, like breast and colorectal cancer, survival has clearly been increasing over time as the mortality has been declining. But there are other cancers that are increasing, for example, pancreatic cancer, which has very low survival. So, when we put the mix together, we see a relatively small change.

We're waiting for an update for our data to actually add a figure for that, but I think, in survival, and I think my NCI colleagues would agree with me, it's important to look at the individual cancers, as opposed to looking at the figure overall...as well as looking at that figure overall.

BOB CROYLE: In terms of the developmental goal of mental and physical quality of life, just last year, we launched a new data linkage between the SEER registries and CMS's Medicare Health Outcomes Survey. So, this is a linked dataset that allows analysis of pre- and post-diagnosis quality of life at a national level for the first time, but this is still in a kind of exploratory area and word and we now have both internal and external investigators analyzing those data, but if you're interested, you can google that or look on the NCI website for the SEER-MHOS dataset.

HOWARD KOH: Thanks. That was Dr. Croyle commenting. Thank you very much. The next question goes to Ms. Cox in Oregon.

Can you comment more about insurance coverage for genetic testing and genetic counseling? I know you have a lot of insurance plans at the table working with you. A questioner says that his or her experience has been that often insurance does not cover genetic testing and genetic counseling.

SUMMER LEE COX: Yes, that's an experience that many of our providers find, as well. There's great fluctuation in Oregon, as well as in other states, between policies and between providers. Both in Michigan and here in Oregon we're working to get some consistency and have the insurance companies follow those evidence-based guidelines, but for those who don't have that work being done in their state right now, there is one option for underinsured people who qualify for testing and that's a group called Cancer One Source. They will subsidize for the underinsured who qualify for testing some of their co-pay or other amounts and that's available nationally So, Cancer One Source. Myriad also offers, for the uninsured, testing at reduced cost or free. The paperwork is perhaps arduous, but well worth it for those who qualify.

HOWARD KOH: Dr. Khoury, do you want to add more on this one?

MUJIN KHOURY: I think Summer is right and there is large-scale fluctuation from state to state about coverage. Just one piece of information, that the consistency with the USPSTF recommendation on BRCA1, that's the G-1 goal, would require coverage of genetic counseling of women with certain types of family history, but does not necessarily extend to the testing. So, it's the first step in a process and, you know, after the counseling, there may or may not be testing.

HOWARD KOH: Great. Dr. Clancy is going to comment, too. This is a good question.

CAROLYN CLANCY: Just to chime in on this a little bit--the current recommendation on the books for BRCA1 and 2 was published, I believe, in '05 or '06. So that predates the Affordable Care Act, in which case the Task Force was focusing on science and people could debate the science and so forth, but whether or not the test was covered was.. they could be implicit and not as specific and concrete as now that their recommendations are directly linked to ACA provisions.

That was very important feedback that we've gotten from a variety of groups and, in particular I think, confirmed the wisdom of the Task Force in engaging stakeholders very early in the process. So I can't possibly tell you... I was going to say, I'd have to shoot you... but that isn't it. I actually haven't seen the draft recommendation and I do believe that they are still working on it as we speak, but I can tell you that this issue is at the forefront of their brains.

HOWARD KOH: Okay. Thank you for the range of good responses on that. The next question is for Dr. Plescia. Dr. Plescia, in your presentation, you alluded to monetary incentives in some programs. Does CDC allow monetary incentives for study participants and, if so, under what conditions?

MARCUS PLESCIA: Yes, that was in the program that we funded in Minnesota to provide incentives to Medicaid beneficiaries to participate in cancer screening. Yes, we do provide...I mean this is an example of a situation where CDC has allowed that. The incentives are relatively small. I think, initially, it was proposed that it be twenty dollars. I think that actually got cut back down to fifteen dollars. But we think this is a compelling area to work on and particularly in the Medicaid population, which can be so hard to reach, sometimes these kinds of incentives can really help overcome some of the other barriers that potential participants are facing.

HOWARD KOH: It's a fascinating area, so-called behavioral economics, right? So, we're at the cutting edge of that...you're at the cutting edge of that. So, thank you very much. The next question is either for Dr. Plescia and/or Dr. Croyle. Can you tell us how effective direct mail reminders are for cancer screenings for unscreened beneficiaries?

MARCUS PLESCIA: Reminder systems for cancer screening are a fairly strong evidence-based strategy. They are featured in the Community Guide to Preventive Services, which is what we've tried to really focus a lot of the grant-based work that we fund in states on. I think the particular question probably alludes back to the one I just spoke to in Minnesota, so this direct outreach to the Medicaid population...that's an area where using reminders, mail reminders or telephone reminders or any kind of reminders, is of real interest to us, because that's a population that has traditionally been so very hard to reach.

BOB CROYLE: There's a lot of continuing work on implementation of reminder systems and I think the challenge is trying to develop reminders that are appropriate for a context and also don't overburden, for example, clinicians, who may receive too many reminders in electronic medical record systems. So, I think we've been... all of our agencies have been receiving feedback as different types of reminder systems have been implemented in community or public health or clinical settings. So, it still continues to be an evolving area, so we know reminder systems are good, but sometimes the devil is in the details in terms of how they're targeted, making sure they are tailored appropriately and also that they're timely.

MARCUS PLESCIA: I'll just add...you know, my dentist and my dog's veterinarian did not miss a beat

(laughter)... They work in a lot of settings, so that we need to use them more in the medical setting.

HOWARD KOH: Very good. Okay.

Let me paraphrase this next question for Dr. Clancy or Dr. Khoury. What's the best way to ascertain a family history of cancer and mutations? Sometimes this information is anecdotal. Can we use genealogic records other than... in addition to medical records to go back further in time? What's the best way to assess this very important history?

CAROLYN CLANCY: Well, I have to say, in my large extended family, this issue comes up a lot, particularly around disease areas that might be very sensitive. For example, half of my family basically would pretend they didn't hear if someone had a breast problem.

You know, in general, we encourage people to review family history, that is, with your family. In fact, a strategy that's been suggested in the past is Thanksgiving...when you see lots and lots of relatives...might be a good time to go over family history. Sometimes, you're going to get stuck, though. It's funny that someone would ask about the genealogical history. It happens that my home is a pretty near the LDS church, where lots of people go to find that out. I am not clear that you would get that kind of very specific disease-based information, particularly going back because, you know, our information... we didn't have as many treatments, so the notion that you would have confirmed diagnoses available to retrieve somewhere feels a little bit magical to me. But, Dr. Khoury?

MUIN KHOURY: Just to add to what Dr. Clancy said, CDC and many federal agencies for the last ten years have worked on a public health family history initiative. It was largely driven by the HHS Surgeon General's family history initiative. For the last ten years, we have promoted the use and for people to gather information about their family history.

It was driven by a survey we did ten years ago that showed that 90 percent of people think family history is important for their health, but less than 30 percent actually collected that information. When you go to your provider for services, there's no time to collect that information, so we tried to empower the consumer to collect that information on their own. Understanding the limitations on what people can gather, there is an online tool, My Family Health Portrait, that's available for free, the Surgeon General's family history tool that has been available. We encourage people to download it. It has multiple diseases, from heart disease, diabetes, a few cancers, and others. We encourage people to collect that information outside the clinical setting and then share it with a healthcare provider. Thanksgiving has been traditionally our sort of family history day, when families get together and get that information. So, if people want more, they can go download that tool freely.

HOWARD KOH: Thank you all. Good information.

Here's a question for anybody. What are the thoughts about whether insurance companies are covering risk-reducing surgeries like prophylactic mastectomy and prophylactic oophorectomy to reduce cancer in BRCA1 and 2 carriers? What's your experience in that or observation from that?

MUIN KHOURY: I can't give you an answer because I think it's still highly variable. That's my short answer.

HOWARD KOH: I think Dr. Plescia is the one for this one. What happens to uninsured patients who receive free screenings and the results come back with positive results? What happens next?

MARCUS PLESCIA: Well, this is a very important area. I mean if people are getting screened for cancer, we need to make sure there's a way to provide them with diagnostic and treatment modalities. In the National Breast and Cervical Cancer Early Detection Program, which is the program I described, we actually have a clause in Medicaid regulations that allows states to provide Medicaid services to women who are screened through those programs. So, it's been a very important part of allowing us to make sure that those women can go on to get the diagnosis and treatment that they need. Now, that's not necessarily true for all screening programs and that's something that we really need to be very diligent about.

HOWARD KOH: Okay, we have about one minute left.

Okay, we're going to take one more question and then wrap up. For Dr. Khoury or Dr. Sondik.

Can you comment on how state cancer registries are getting worse?

ED SONDIK: Yeah. Very briefly; the measure is based on the percentage of cases that are estimated and whether or not the state cancer registry captures a particularly high percentage of cases that are estimated. This can vary over time. The difference that's shown here is actually a very small difference and that's why it's going in the wrong direction. I think this is another one where we need to look at some data over time. I think the figure was that 43 states, or thereabouts, met it, met the baseline, and then that dropped down to 42, but that could be a function of, perhaps, a shortage of people in the state. It could be that data doesn't come into the state registry on time. It might be a couple of months late, or a month late for that matter, and this could make a difference. So this is something that I would watch, but I'm not upset by it.

HOWARD KOH: Okay, Dr. Sondik. Thank you so much. We have 30 seconds left and, in that last 30 seconds, I want to acknowledge the leadership of the workgroup members from the Cancer and Genomics Topic Areas of Healthy People, who have coordinated this absolutely fabulous webinar.