

Advisory Committee on Breast Cancer in Young Women

**Virtual Meeting
August 23, 2022**



Record of the Proceedings



Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control



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Introduction

The US Department of Health and Human Services (HHS) and the Centers for Disease Control and Prevention (CDC)'s National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control (DCPC), convened the teleconference of the Advisory Committee on Breast Cancer in Young Women (ACBCYW) on August 23, 2022.

ACBCYW is a federal advisory committee that is formally chartered to provide advice to the HHS Secretary and the CDC Director regarding the formative research, development, implementation, and evaluation of evidence-based activities designed to prevent breast cancer in young women (particularly those at heightened risk).

Information for the public to attend the ACBCYW meeting by audio or web conferencing was published in the *Federal Register* in accordance with Federal Advisory Committee Act regulations. All sessions of the meeting were open to the public.

Opening: Welcome, Roll Call, and Introductions

Speaker: Kimberly E. Smith, MBA, MHA
Designated Federal Officer
CDC, Division of Cancer Prevention and Control

Ms. Smith called the meeting to order at 11:00 a.m. EST. She welcomed the participants to the virtual meeting and thanked the committee members for their time and commitment. Members of the public were also welcomed, thanked for their interest, and given the reminder that, before the conclusion of the meeting, there would be a period for public comment. Ms. Smith also instructed members of the public that if they would like to make a comment, they could email ACBCYW@cdc.gov to indicate their interest in speaking during the public comment session at the end of the meeting.

Ms. Smith conducted roll call and confirmed 11 voting members, 3 ex-officio members, and 8 liaison representatives (or their proxies) in attendance. This constituted a quorum for the ACBCYW to continue with the meeting on Tuesday, August 23, 2022. There were no publicly declared conflicts of interest by the voting members for any of the items on the published agenda (see Appendix A: Meeting Agenda).

Speaker: Lisa C. Richardson, MD, MPH
Director
CDC, Division of Cancer Prevention and Control

Dr. Richardson presented on CDC's Role in Cancer Prevention by beginning with a brief overview of DCPC's strategic plan, which has a vision of "All People Free of Cancer." The strategic plan consists of aspirations, strategic priorities, guiding principles, and strengths. When Dr. Richardson became director, she believed in keeping the strategic plan as succinct as possible, so there is not a 500-page document to support the strategic plan. She suggests that the absence of a lengthy supporting document to the strategic plan allows for nimbleness when changes need to be made.

The strategic priorities in the strategic plan are (1) reduce risk of cancer, (2) scale best practices to increase screening outcomes, and (3) improve health and well-being for cancer survivors. Quite a bit of the work that is done in young women falls within survivorship.

Dr. Richardson shared the 2022 appropriations from Congress to show how funding is dispersed. The majority of the funding in DCPC, \$196.8 million, is part of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). DCPC comprises the Office of the Director and four branches. Each branch houses a specific program. The Cancer Surveillance Branch houses the National Program of Cancer Registries (NPCR), which complements the Surveillance, Epidemiology, and End Results (SEER) registry administered by the National Cancer Institute (NCI). NPCR collects information that is not currently collected by the SEER registry. When the NPCR information is combined with SEER, there is a 100% count of all cancer cases in the United States, every year. The data come from multiple sources, including hospitals, pathology labs, doctor offices, data set linkage, and 50 central cancer registries, and are then transferred into CDC's Data Visualizations tool.

Next, CDC's National Comprehensive Cancer Control Program was highlighted. This program has coalitions in all 50 states, 7 US territories and freely associated states, and 8 American Indian and Alaska Native tribes, with a focus on the following outcomes: primary prevention; early detection; survivor health and well-being; policy, system, and environmental change; health equity; and evaluation and outcomes. Of these outcomes, Dr. Richardson focused on evaluation and health equity. Evaluation is an important step that is interwoven into everything that is done at CDC. Health equity was explained as a pillar of both DCPC and its programs. It is a cross-cutting goal for the Comprehensive Cancer Control Branch and one of the guiding principles of DCPC.

Dr. Richardson also explained the importance of partnerships. A snapshot was given of some of the partners that work with the Comprehensive Cancer Control Program. These partners were described as a group of volunteers who help DCPC think through the specifics of cancer control.

Dr. Richardson also discussed the improvement of access to quality care through the efforts of the NCCCEDP and Colorectal Cancer Control Program (CRCCP). NCCCEDP has provided services for 31 years, screened over 6 million women, and provided over 15.6 million breast and cervical cancer screening exams, with 27,000 breast cancer diagnoses. CRCCP is a health system change program. Although services are not provided directly through CRCCP, 35 programs are funded to work with clinics and health systems to implement evidence-based interventions.

Dr. Richardson continued by explaining the importance of looking at cancer risk and family history for breast, ovarian, colorectal, and other hereditary cancers. She also explained that hereditary breast and ovarian cancer are an important part of the work done in DCPC, but there are many gene and familial genetic syndromes. Progress has been made in the genetic realm of figuring out what causes cancer, familial cancer in particular, and it has been found that early detection is key. Generally, people may be screened 10 years earlier than the recommended starting age for screening because later-stage cancer can be more aggressive and harder to treat.

People who have a family history of cancer or who carry pathogenic variants are at increased risk for additional primary cancers, like prostate and pancreatic cancer. If a person does not have a pathogenic variant, it does not mean that they are not at higher risk. Dr. Richardson stressed the importance of exploring familial history and described familial history as the original genetic test.

CDC's Cancer Genomics Program concentrates on hereditary breast and ovarian syndrome and Lynch syndrome. For Dr. Richardson, it's about taking all of the work that has been done through the Cancer Genomics Program and moving it forward. One thing that is understood is that the same genes can cause multiple cancers. Genomics surveillance work was reviewed, and Dr. Richardson encouraged the participants to take an in-depth look at the work that has been done. Some of this work includes expansion of data collection systems to include genomic fields, targeted public health efforts, and informing policy and system change with health system-level data.

A great deal of effort went into getting biomarkers, other than the five parts of cancer, because they are important for prognosis and response to therapy. Dr. Richardson explained that, through NPCR, efforts have been made to collect data faster and more accurately. Data that include information about biomarkers will allow clinicians to predict long-term outcomes by helping to identify patients who may be at risk for genetic syndromes.

The surveillance vision for the future is cloud-based, immediate reporting at the time of care. This reporting would go directly to a cloud platform where all software tools are housed, allowing for quicker transmission of data. In clinical trials, a reporting system like this would be paramount, because at the time someone is diagnosed—if they give permission—there will be notification that a cancer was newly diagnosed. Evaluation can then take place to determine if the person diagnosed is eligible for a clinical trial.

Dr. Richardson discussed other efforts like the Cancer Screening Change Package, which includes comprehensive tools and resources to improve awareness, access, community-clinical linkages, and screening use. She also discussed communication tools that use an interactive avatar to allow patients to ask questions in areas such as Creating Healthy Habits for Breast Cancer Recovery, Reducing Infection Risk During Chemo, and Understanding your Family Health History and Risks.

Dr. Richardson also discussed a research project funded in 2021 that seeks to reduce inequities in cancer outcomes through community-based interventions that address social determinants of health. The advantage of this work is it is being done at the community level specifically to benefit community members. Lastly, Dr. Richardson addressed the topic of shaping health behavior. Through funding from the CDC Foundation, a 3-year program is being launched to develop innovative approaches to empower patients to be proactive participants in their own care.

Questions and Answers

The first question came from Dr. Marisa Weiss, who represents Breastcancer.org, who asked, "What are some of the resources for community-based organizations to help address social determinants of health to improve clinical trial participation?" Dr. Richardson responded that most of the work is done in collaboration with the NCI, but she could not think of anything that specifically deals with clinical trials.

The next question was from member Rebecca Seago-Coyle, who asked, "From my experience, there seems to be a delay in SEER data when it comes to when someone was diagnosed or the death date. How are we addressing getting the data sooner?" Dr. Richardson responded that the National Vital Statistics System has death data complete through the end of 2021. Also, CDC Wonder has provisional death data through May 2022. However, Dr. Richardson pointed out that, to improve cancer registry data, we need to understand how to use the cloud and how to use direct reporting from the source for information about people diagnosed with cancer. Right now, it takes 30 months to go from diagnosis to data being reported on the CDC website.

Speaker: Cristina M. Checka, MD
The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

Dr. Checka welcomed everyone and shared that she was pleased to serve as the new chair of the ACBCYW. She then introduced herself and moved to opening the floor for members to give brief introductions (Appendix B: ACBCYW Public Roster).

CDC Updates

Speaker: Stephanie Melillo, MPH
Health Scientist
CDC, Division of Cancer Prevention and Control

Ms. Melillo served as the acting subject matter expert for Dr. Temeika Fairley. Ms. Melillo provided background on breast cancer diagnosis in women younger than 45.

Ms. Melillo discussed the Breast Cancer Education and Awareness Requires Learning Young Act (EARLY Act). This is the first piece of legislation related to breast cancer in young women, enacted in 2010. The EARLY Act authorized CDC to:

- Develop initiatives to increase awareness of breast health and breast cancer risk among young women.
- Establish the federal Advisory Committee on Breast Cancer in Young Women (ACBCYW).
- Establish an applied public health research program about breast cancer in young women.
- Establish a program to provide support to young women living with breast cancer.

The members of ACBCYW were thanked by Ms. Melillo, and she reminded the participants that the recommendations made by the committee at the last meeting are currently with CDC and HHS for consideration.

Different approaches that DCPC have taken under the applied public health research category were explored by Ms. Melillo. These approaches included looking at data from existing studies, surveying data and linking them to registry data, and collaborating with researchers at the Prevention Research Centers, which have expertise in modeling strategies.

CDC funds organizations across the country as part of cooperative agreements designed to enhance survivor support and increase the availability of services and support for young breast cancer survivors and for metastatic breast cancer patients and their families. Currently, there are eight organizations that are funded to provide this support.

Ms. Melillo reiterated that young breast cancer survivors and people living with metastatic breast cancer often face difficult medical, psychosocial, and other health issues related to their diagnosis and treatment. They have distinct challenges that affect their physical and mental health. Funded organizations work within communities, know the challenges that community members face, and are well-positioned to help advance this work.

The metrics and progress of the *Bring Your Brave* campaign were presented. This campaign focuses on young women and the health care providers that serve them. The purpose of the campaign is to extend the reach of educational messaging through various platforms, like social media, podcasts, and television. From April to June 2022, there were 159.8 million campaign impressions that led to 1.73 million visits to CDC's *Bring Your Brave* website.

The campaign also includes a health care provider component. Work has been done in collaboration with the National Association of Chronic Disease Directors to make informational videos about early onset of breast cancer. The videos are currently available on the *Bring Your Brave* website and YouTube. On both platforms, there are links to additional resources. CDC also partnered with Medscape to bring two continuing medical education (CME) modules that resulted in over 29,000 learners and over 20,000 CME credits issued. In a separate project, CDC partnered with the American College of Obstetricians and Gynecologists (ACOG) to create a 14-credit CME course, which was launched in 2020. This course led to 3,768 course registrations and over 13,000 CMEs awarded. Of those who completed the post-course survey ($n = 231$), 99% said they would recommend the course to their colleagues. Of those who completed the follow-up survey 3 months after the course ($n = 78$), 84% reported implementing the information from the course into their practice.

What's new and what's next for the *Bring Your Brave* campaign is entertainment messaging—specifically, putting messaging into television shows. For example, the medical drama *New Amsterdam* featured a storyline about breast cancer as part of Breast Cancer Awareness Month.

CDC is also using a new interactive tool called Let's Talk to allow users to practice discussing hereditary breast and ovarian cancer risk with family members. The Let's Talk module includes videos of women who share their stories about how they were affected by hereditary breast and ovarian cancer and how they plan to share their stories with their families in the future.

CDC also developed an app called My Family Health Portrait: Cancer to help users determine their risk for different hereditary cancers. The app includes a visual pedigree chart and supports patient and health care provider discussions about the patient's family history of hereditary cancers. The *Bring Your Brave* campaign is also working on a mobile game narrative integration. For this work, CDC partnered with a team of people led by women of color to reach young black women with messages about breast cancer. These messages will be included in Glow Up Games' mobile game *Insecure: The Come Up Game*, which is based on the hit television show.

Opening Presentation

Speaker: Cristina M. Checka, MD

The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

Dr. Checka provided an overview of her presentation that included pertinent statistics. She stated that breast cancer represents 5.6% of all invasive disease among people aged 15 to 39. However, when looking at women younger than 45, there is an uptick at age 40—11% of all breast cancer diagnoses are increasing in this age group, which is about 26,500 annual cases. Dr. Checka shared that the uptick in incidence is possibly twofold. There is probably asymptomatic disease that's detected by screening protocol that typically starts at age 40. However, that's also the point where the inflection point starts to reflect that the disease becomes more common among people in their 40s, 50s, and 60s, which is why screening protocols for women at average risk begin at age 40.

When comparing younger women to older women, younger women tend to present with more advanced disease, including more cases of de novo stage IV disease, where patients already have metastatic disease outside of the breast and regional lymph nodes. This finding could be because people in this age group are typically not screened, and those who are screened have a known high risk. In terms of race and outcomes, black women younger than age 35 have a higher incidence of invasive breast cancer and a three times higher mortality rate compared to young white women. Overall, advanced-stage diseases are more common in young patients who are Black, Hispanic, or American Indian or Alaska Native and in all patients with lower socioeconomic status.

Knowledge of personal risk and family pedigree are particularly important to understanding risk factors for breast cancer in young women. For example, earlier menarche, later age (>30) of first full-term birth, and postpartum hormonal milieu are hormonal risk factors for pregnancy-associated breast cancer. Lifestyle and other personal risk factors, such as alcohol use, can also substantially increase risk. Physical inactivity and increase in body mass index after age 18 can promote a two-fold increased risk for ER-negative breast cancer.

Dr. Checka listed issues for young women with breast cancer, including fertility preservation (e.g., access, cost, options), premature menopause, postsurgical reconstruction (e.g., access, cost, options), and body image. She asked participants to think of where financial toxicity may come into play. Access and being able to pay for things like fertility preservation and surgical reconstruction should be considered not only in urban settings, but in rural and less-populous areas of the country as well.

The multimodal treatment journey was illustrated, beginning with screening and high-risk surveillance, for patients who know their risk. Dr. Checka suggested that the

challenge is that the right patient knows her risk and is appropriately accessing high risk surveillance protocols. Next on the multimodal treatment journey was timely diagnosis and access to care. This is a time when genetics or unknown genetic information may come to light, either because the patient is connected with appropriate genetic testing because of family history, or she presents with breast cancer at a young age and is indicated to have genetic testing. Timely diagnosis and access to care can be slowed by the dismissal of a patient's concerns, resulting in a delayed diagnosis.

Another issue is access to reconstructive surgery and its effect on sexuality. For survivors, there is an effect on sexuality, but the focus is switched to wanting to increase wellness. Dr. Checka shared that she discusses wellness with her patients from the time of diagnosis. Wellness is important because it will not only reduce the risk of recurrence, but also reduce a young patient's risk of other cancers. Late effects of treatment include cardio toxicity, premature menopause, loss of bone density, neurocognitive challenges, and post-traumatic stress disorder that can happen even years after treatment. Surveillance is necessary but can be concerning because the hope is that young patients will survive at least two decades of life, and the cost of care can add up. Dr. Checka said researchers are working to evaluate the best type of studies for surveillance of cancer survivors.

Psychosocial support spans the total spectrum of the multimodal treatment journey and is a need that continues beyond the acute phase of care. Dr. Checka spoke of patients' experiences of having their concerns dismissed by a medical provider.

Dr. Checka then reminded meeting participants about the current ACBCYW workgroups, which are:

- Mental/Behavioral Health Workgroup
- Provider Workgroup
- Sexual Health and Fertility Workgroup
- Genetics and Genomics Workgroup

For ACBCYW members who had not had an opportunity to review the meeting minutes from the November 2020 meeting, Dr. Checka gave a brief overview.

- **CDC Updates:**
 - *Bring Your Brave* campaign, launched in 2015.
 - CME course co-sponsored with ACOG: Early Onset Breast Cancer Education Program, June 2020.
 - Co-sponsored podcast with National Society Genetic Counselors.
- **Barriers to Care Presentation (FORCE):**
 - Previous work centered on *BRCA* carriers expanded to other patients at high risk because of family history, other gene mutations, or both.

- Multigene panel testing has become the standard of care and costs \$250 or less.
- US Preventive Services Task Force recommendations do not address the needs of all patients at high risk and insurance carriers who rely on these recommendations for coverage decisions.
- Looking at normal costs versus exacerbating costs through an equity lens is also important.
- **Mental/Behavioral Health Workgroup**
 - Work centered on:
 - Extensive literature review.
 - Primary interviews with patients and subject matter experts.
 - Major concerns persist even years after active treatment, including fear of recurrence, depression, anxiety, stress, suicidal ideation, and post-traumatic stress disorder.
 - Gaps in effective uptake of services identified.
 - Mental/Behavioral Health Workgroup Recommendations:
 - Support screening to identify patients at high risk for breast cancer and survivors for mental health issues.
 - Provide funding to clinics and health care systems to support mental health services for cancer patients.
 - Allocate resources for dedicated research on mental health in young women with breast cancer.
- **Provider Workgroup**
 - This workgroup focused on the early impact of the COVID-19 pandemic on rate of diagnoses, delayed presentation of disease, decreased screening. These effects and outcomes are still being examined in 2022
 - Provider Workgroup Recommendations:
 - Create a one-stop shop of materials on the CDC website. Strong user experience necessary to meet the needs of providers with varying needs and must acknowledge inconsistencies.
 - Develop simple, supplemental educational materials for providers to address gaps in content.
 - Develop a comprehensive promotion plan to amplify the new resource and encourage more use of existing resources.

- Identify process to ensure regular review and timely updating of the one-stop shop with new recommendations and resources as needed.
- **Sexual Health and Fertility Workgroup**
 - Two problems were identified when this workgroup was first formed:
 - Lack of consistent acknowledgement, assessment, and interventions offered for sexual health concerns in young women with breast cancer.
 - Lack of consistent acknowledgement, assessment, and interventions offered for fertility concerns in young women with breast cancer.
 - Dr. Checka amplified a comment about the significant difference in sexual health concerns and fertility concerns. Sexual health may be strongly aligned with mental health and the need for mental health support. Fertility concerns may be aligned with a need for intervention.
 - The workgroup felt that the National Comprehensive Cancer Network guidelines released in February 2020 were insufficient and lacked advice in how to address the needs of young women.
 - Sexual Health and Fertility Workgroup Recommendations:
 - Sexual health should not be listed under survivorship but should instead have its own CDC guidance area.
 - Experts in the field (sexual health and fertility) should develop specific content for CDC to include on its website.
- **Genetics and Genomics Workgroup**
 - The group identified several challenges that providers and the public may face with regard to genetic and genomic testing. They include:
 - Confusing terminology.
 - Large number of tests; knowing which test to use when and how to interpret results can be challenging to untrained professionals.
 - Uncertain benefit of various genetic and genomic tests.
 - Lack of health insurance coverage for testing.
 - Limited access to consumer genetic testing kits.
 - Different types of risk, making it hard to synthesize individual risks to provide a total risk estimate; prediction programs outdated.
 - Genetics and Genomics Workgroup Recommendations:
 - Support and provide educational materials for understanding terminology related to genetics, genomics, and various types of testing.

- Synthesize available and reliable information in central location and develop an educational platform on genetics and genomics for providers and the public .
- Consider the question, “Should we explore education regarding pathologic risk?”

Dr. Checka concluded her presentation with a discussion of committee membership and leadership, the cadence of workgroup meetings, and consideration of adding a third meeting in 2023.

Presentation: Cured into Destitution: Financial Toxicity in Breast Cancer

Speaker: Anaeze C. Offodile II, MD, MPH

The University of Texas MD Anderson Cancer Center

Assistant Professor, Department of Plastic Surgery, Division of Surgery

Executive Director, Clinical Transformation, Division of Office of the Chief Medical Executive

Dr. Offodile started by noting that his presentation, Cured into Destitution: Financial Toxicity in Breast Cancer, reflected 3 to 4 years of scholarship by many collaborators. He discussed medical debt in the United States, noting that we are the only industrialized country where people have significant medical debt. About 80% of Americans have some form of medical debt. In 2014, for the first time, medical debt outpaced nonmedical debt in the United States, and in 2019, 60% of this debt was above \$1,000. In 2020, total medical debt in collections was \$140 billion.

These statistics set up the term *financial toxicity*, which is defined as the negative impact that high costs of cancer treatment can have on a patient's quality of life. Dr. Offodile modified this definition to include the indirect costs of cancer treatment on patients and their caregivers, as both are affected. Factors associated with financial toxicity include cancer type, personal savings, insurance coverage, and age (specifically young adults).

Cancer is the second most expensive chronic disease after heart disease. This is because of the structure of cancer care. There is so much innovation with diagnosis and treatment, which comes with a high cost. Cancer treatment often includes overtreatment, especially at the end of life.

Dr. Offodile described cancer as an economic shock and shared graphics that show that cancer care is abrupt and expensive, which increases cancer patients' risk for financial toxicity and bankruptcy. In one study (*J Clinic Oncol.* 2016;34(9):980–986), researchers used propensity score matching to examine pairs of adult cancer patients who had filed for bankruptcy and those who had not. The study found that bankruptcy appeared to be

an independent risk factor for mortality. Those who filed for bankruptcy had worse overall propensity scores. For breast cancer patients who filed for bankruptcy, almost 2% had higher odds of overall mortality.

Dr. Offodile also described the following three domains of financial toxicity:

- **Material conditions**, which include out-of-pocket expenses, missed work, reduced or lost income, medical debt, and bankruptcy.
- **Psychological response**, which includes feelings of distress due to the costs of cancer care and concerns about whether wages or income will cover expenses related to these costs.
- **Maladaptive coping behaviors**, which include skipping or taking less of medication and delaying or missing doctor visits.

Dr. Offodile uses a conceptual framework that breaks financial toxicity down into causes and consequences. When put together, they create a spiral effect. People with risk factors related to their demographics, socioeconomic status, age, cancer type, cancer stage, insurance status, or treatments begin to embody consequences of toxicity. This results in stress, which feeds into increasing debt, low quality of life, less ability to work, and less savings.

According to the American Society of Clinical Oncology's 2018 National Cancer Opinion Survey, more patients were concerned about financial burden than death. This finding shows that financial toxicity affects both survival outcomes and quality of life. Another key point raised is that financial toxicity is not just centered on the patient, but also on immediate families. Sixty-one percent of caregivers said they have taken at least one onerous step to pay for a loved one's cancer care. These key findings are a dominant issue in the policy patient advocacy and care delivery landscape, and their effect will be felt even more after the COVID-19 pandemic. A lot of abrupt economic discontinuity happened during the pandemic, and Dr. Offodile believes it will drive a lot of financial toxicity moving forward.

The concept of financial toxicity has gained traction in the press, and breast cancer appears to be the exemplar condition to articulate why financial toxicity is so burdensome. Dr. Offodile noted that financial toxicity is more of a medical term, not something spoken by patients. However, the language used by people with cancer addresses similar themes: concerns about having limited resources, having to exhaust resources like savings, or having to rely on family members to cover financial gaps. Another theme is career disruption, such as concern about being passed over for promotion because employers fear that, if a person gets cancer again, they will have to pay for medical disability. Subsequent indirect costs are also a concern of people with cancer, such as costs for travel, lodging, and childcare associated with treatments and doctor's visits.

Several key instruments are used to measure financial toxicity. The instrument used by Dr. Offodile is an 11-item score instrument that measures from 0 to 44, where lower

values means worse toxicity. Dr. Offodile cited a systematic review (*J Natl Compr Canc Netw.* 2019;17(10):1184–1192) that examined 74 studies that used the 11-item score instrument and found that 49% of patients reported some form of financial toxicity. Those at higher risk were uninsured, had lower income, were young, were unemployed, and were members of racial minority groups. The effect of financial toxicity was associated with medical nonadherence, worse psychosocial outcomes (specifically quality of life), and worse survival outcomes.

Dr. Offodile provided further context for financial toxicity through a framework that looked at:

- Antecedents:
 - Cancer diagnosis at age 15 to 39.
 - Precancer financial status.
- Attributes:
 - Competing financial pressures (e.g., career aspirations, student loans, ongoing financial responsibilities).
 - Financial burden of treatment.
- Consequences:
 - Damaging financial problem-solving behaviors (e.g., withdrawing money from accounts early, not adhering to treatment), material hardship (e.g., inability to pay rent or mortgage), and deteriorated quality of life.

Dr. Offodile explained that he chose to focus on breast cancer surgical patients in relation to financial toxicity because he wants to expand the evidence base. There are limited data on causes and consequences in the area of surgical oncology. Additionally, breast cancer is expensive, with treatment costs that are the highest among solid tumors, and it has the steepest trajectory. Dr. Offodile went on to say that breast cancer is preference sensitive, meaning there are various treatment paradigms. A patient can have varying treatment options (e.g., breast cancer treatment, mastectomy, contralateral prophylactic mastectomy) that result in equal outcomes, but with varying costs. Because cost has been shown to influence treatment decisions, Dr. Offodile highlighted the importance of explaining to patients with breast cancer the associated costs of treatments that will ultimately have the same survivorship. This is an opportunity for clinicians to drive decision making in a way that could prevent or protect against financial toxicity. Cost has been shown to influence decisions in care. Dr. Offodile cited an article (*J Oncol Pract.* 2019;15:e666–676) that shows that women with annual household income less than \$45,000 prioritized costs of treatment over breast preservation or appearance.

Dr. Offodile transitioned to the work he and his team are doing at MD Anderson around risk factors and attitudes about cost discussions in comprehensive breast care, which is

defined as surgical oncology, plastic surgery, radiation oncology, and hematology oncology. The team administered a single-institution, 29-item patient survey that found predictable results: income tracked to financial toxicity. Breast cancer patients who were older and who had higher incomes and higher credit scores experienced less financial toxicity. Younger patients were shown to be at a higher risk of financial toxicity. It is important to note that the population at MD Anderson is not generalizable; patients tend to be White, affluent, and privately insured.

The survey also examined the frequency and importance of cost discussions. Breast cancer patients who underwent surgical care at MD Anderson were asked if they had discussed costs with a member of the surgical team; 87% said they had not. They were also asked if they believed their plastic surgeon should consider cancer treatment costs when providing a patient with treatment recommendations. Forty-eight percent (48%) said it was a significant factor in planning. Similar work came out this year that reproduced Dr. Offodile's team's findings. It was deduced that cost discussions are important because they create an emotional space for women to consider cost in their decision making. Such discussions also provide an opportunity to find out who is high risk and refer them to the appropriate resources, either within the institution or externally.

Secondly, cost discussions are important because they dampen the incidence, severity, and trajectory of financial toxicity. This is important in the context of breast cancer surgical patients because financial toxicity affects quality of life. Dr. Offodile wanted to know if financial toxicity should be looked at as a marker for surgical care quality in breast cancer. This is a difficult problem to address that will require multi-level solutions that cut across policy, state, and institutional levels. For example, under the 2022 Inflation Reduction Act, Medicare beneficiaries have limits on out-of-pocket costs for their care, which means Medicare can now negotiate directly with pharmaceutical companies. The Biden Administration enlisted a protection whereby medical debt does not injure the credit report. Dr. Offodile advised that multi-level solutions are imperative and solutions must exist through enforcing systemic, institutional, and interpersonal frameworks.

Dr. Offodile said he is enthusiastic about financial navigation in cancer care, its potential impact on cancer care, and how it can be used in oncology as an instrument to reduce financial toxicity. A proposed mitigation strategy for reducing financial toxicity includes cost discussions and financial literacy, screening tools, a de-emphasis on low-value care, changes to care plans, and use of financial navigation.

Questions and Answers

The first questions were, "What is the percentage of people having conversations with their health care professionals without having financial navigation? Could that lead to people choosing below the standard of care? Is that a concern? How does financial navigation mitigate people choosing below the standard of care? To what degree is the

financial navigation piece able to mitigate that?" Dr. Offodile replied that in one of the articles he referenced in his presentation (*JCO Oncol Pract.* 2021;17(6):e872–881), researchers were able to get transcribed conversations that showed that cost conversations did indeed dampen financial toxicity incidents. The role of the clinician is to contextualize the treatment options to the patient's financial situation. The most important part is to gain a sense of what matters to the patient and her family. For example, if a patient is not looking to go bankrupt, wants less downtime, and does not want to rely on financial assistance from caregivers, then the clinician would not offer reconstructive surgery. Therefore, the treatment will be aligned with what matters most to the patient. The role of financial navigation is not to track the clinical delivery domain, but to help with things like copay assistance, changes to a benefits plan, or direct monetary aid. Dr. Offodile added that the root cause of financial toxicity in the United States is our dependence on the free market. The government does not provide health care the way governments do in other countries.

Dr. Offodile asked meeting participants what they thought could be done to create more visibility on this issue. He also raised the question of whether cases of breast cancer have been increasing among young women over time, and if so, how is financial toxicity affecting these women long-term?

There was more discussion around cost as a higher priority than breast preservation. It was also noted that most tests are done from a blind cost spot because it is inherently what is done (e.g., the mammogram, the ultrasound, and the MRI are done because that's the course of action to get to diagnosis). If a person presents with a lesion in one breast, then the next step would be to check the other breast, but this is done without having a cost conversation about the financial ramifications.

There was a question about metastatic disease. Dr. Offodile responded that chronic maintenance therapy will likely lend itself to more financial toxicity. A subsequent comment was that there is an emotional context in which these decisions are made by the patient. People diagnosed with breast cancer want everything done as quickly as possible without looking at the cost. There is a cognitive dissonance of looking at the cost as urgent decisions are being made. Most people approach the cost discussion from the vantage point of getting what is needed and worrying about cost later.

Before the onset of the next agenda item, Open Discussion, roll was taken, and a quorum was constituted to continue with the ACBCYW meeting.

ACBCYW Open Discussion

Speaker: Cristina M. Checka, MD
The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

Dr. Checka began by introducing the agenda item of establishing workgroup membership and workgroup leadership. Additionally, Dr. Checka opened the floor to open discussion on the direction members would like to see the committee go, including brainstorming ideas for the 2023 agenda and whether to add a third meeting in 2023.

As it relates to the direction in which ACBCYW should go, it was suggested that the committee not “reinvent the wheel.” A great deal of effort is put into setting the agenda versus actually doing the work. In order to move forward with the work, the first step in each workgroup should be gaining an understanding of what has been done and knowing where progress has been made. There are topics that have not been addressed, there are topics that have been addressed but are not completed, and there are topics that have been addressed and the work is completed. Once that is understood, that information can be used to guide next steps.

As a reminder, Dr. Checka named the four workgroups and provided the frequency for the ACBCYW meetings, which take place twice a year—one meeting in person and the other meeting virtually. The workgroups have a more frequent cadence, with schedules determined by workgroup members.

For new members, the question arose of which workgroup they could best contribute their lived experience and research. For someone who is interested in education, delays in diagnoses, difficulties in diagnoses, or patient dismissal, the Provider Workgroup would be most fitting. It was noted that education is important, but culturally competent education is of the utmost importance. It was noted that Black women are the disparate population because black women are 40% more likely to die from breast cancer. Disparities is a cross-cutting topic that all four of the workgroups will address.

It was further postulated that a tremendous amount of work needs to be done at the community level to raise awareness about breast cancer, especially among young women who are told repeatedly that breast cancer cannot happen to them. A question was raised about whether there are any unintended consequences related to some of the specific messaging around familial history and knowing one's risk. Dr. Checka responded that there is potentially a gap in patient education, but it's not just among young women, because a majority of patients with solid tumors don't have an antecedent family history. She said it's the fluency that the general population has about assessing individual family history and risk that is a huge gap.

In terms of provider education and health disparities, members noted that there is a great deal of education available, but it is scattered broadly and not easily accessible. One of the recommendations from the last ACBCYW meeting is that CDC take on the task of consolidating available evidence-based information into an online one-stop shop that is user-friendly for providers. A question was raised about what is being done to incentivize providers to go get the education they need. A lot of pressure is put on the patient to be educated, but it was suggested that there should be more pressure and incentive for providers to be educated as well.

Another discussion point was that breast cancer may not be on the radar of primary care providers or ob-gyns, especially since some ob-gyns don't perform breast exams. A question was raised about how ACOG is dealing with the U.S. Preventive Services Task Force change in guidelines. Dr. Myrlene Jeudy, a representative from ACOG, responded that ACOG is still recommending that ob-gyns address breast health in annual visits and postpartum visits with their patients. The challenge is the multiple requirements for annual visits, which can result in some providers stressing one topic over another. There is also a lot of controversy in the field about doing breast exams versus not doing breast exams. Some providers and other subject matter experts state that breast exams are not needed for women at average risk, but Dr. Jeudy argues that, if providers are not risk-stratifying patients accurately, they don't know patients' true risk. ACOG members are debating whether to recommend breast exams or not.

It was also pointed out that there is not an individual risk-based screening guideline at this time; everything is one-size-fits-all unless you're at high risk. Dr. Checka commented that, as a specialty surgeon, she does not require a patient to have a cancer diagnosis before they can be seen by her. But patients normally need a referral before they can see a specialty surgeon. Dr. Checka suggested that a more efficient practice would be for patients to know that she is available to address any concerns that they or their primary care provider might have.

The question of breast awareness verses self exams and knowing the difference between the two arose. Committee member Melissa Peters shared that, when she surveyed young women diagnosed with breast cancer, 62% said they were never educated by their providers on breast awareness. Women also reported that, when providers were doing their breast exams, they engaged in meaningless conversation instead of educating them about what they were checking for. Ms. Peters felt this would be an opportunity to educate the patient and talk the patient through what the provider is feeling for. After Ms. Peters spoke with providers in her community about educating patients during exams, many providers said they don't have time to educate patients and perform breast exams. The suggestion was made to have materials in the waiting room that patients can read instead.

Another question raised was, is the proportion of young women who are living with metastatic disease known and is there a larger portion of young patients in survivorship? Committee member Dr. Maryam Lustberg said survival has increased. As a survivorship research leader, Dr. Lustberg stated that the focus may not have been on the unique needs of metastatic survivorship.

It was expressed that palliative care should be introduced to young women who are diagnosed with later-stage breast cancer. The misconception is that palliative care is hospice care. They are not the same thing.

Dr. Checka refocused the open discussion to ask members to make a decision about whether to keep the current four workgroups and fit the work into these categories or shift the focus and perhaps trade out a workgroup or two. In order to trade out a

workgroup, there is an official process that must be followed. Dr. Checka asked should we keep these same four workgroups and find ways for the concerns and questions and directions that we've identified today in this open discussion, or is there a need to switch out workgroups?

Before deciding on workgroups, a question was raised about what were the agreed-upon next steps for addressing disparities, health equities, and social determinants of health in the different workgroups. Dr. Sue Friedman, representative for FORCE, responded to this question by recalling that, as the workgroups were formed, marching orders and tasks were given and each workgroup was told to address disparities. Dr. Checka followed up with the thought that, because disparities underline all of the topics being addressed, maybe their actions should be more deliberate and accountable to make sure disparities are specifically addressed by each of the workgroups.

It was suggested that education should be cross-cutting across all four workgroups as well. The need to set incremental goals to measure success was also mentioned, along with the idea of collecting status reports to share what was accomplished, what is still left to do, and input from all group. Members were cautioned to not get bogged down in trying to address all social determinants of health and to agree on which definition of social determinants of health will be used.

Dr. Checka then moved to ask members to vote whether to keep the same workgroups or change the workgroups.

Mental/Behavioral Health Workgroup

- There were no motions to discontinue the Mental/Behavioral Health Workgroup, so the default is to continue with this workgroup.

Provider Workgroup

- A lot of discussion around the changing of the name of this workgroup took place. Ms. Smith advised the members that the name does not have to capture everything that is going to be done in the workgroup; what's important is the charge for the workgroup.
- Committee member Rebecca Seago-Coyle brought forth a motion for the Provider Workgroup to be changed to the **Provider and Healthcare Systems Workgroup**. Committee member Rebecca Muñoz seconded the motion.
- There were enough votes to pass the motion.

Sexual Health and Fertility Workgroup

- Before voting took place, Dr. Checka suggested that it would be helpful to look at past discussions about how sexuality is more of a behavioral and mental health component, while fertility is more of a medical intervention.
- A lot of discussion took place around the renaming of this workgroup to include maternal health since fertility is a part of the original name.

- Member Dr. Heather Ochs-Balcom brought forth a motion for the name of the Sexual Health and Fertility Workgroup to be changed to the **Reproductive Health Workgroup**. Member Ashley Dedmon seconded the motion.
- There was only one no vote, so the motion carried.

Genetics and Genomics Workgroup:

- Members did not suggest a name change for this workgroup.

Public Comment

No written comments were received. However, two responses were received in the mailbox during the virtual meeting from people who wanted to comment.

The first public comment came from Samara Spence:

Ms. Spence stated her name, thanked the committee for the work being done, and proceeded with her comment. She was diagnosed with metastatic de novo breast cancer at the age of 40. She had no family history and no known risk factors. She educated herself with materials provided by some of the organizations represented in this meeting. Ms. Spence presented the committee with two comments. The first comment was about detection and the education around detection. Her belief is that detection and the education around detection needs to go to public messaging, as well as the conversation that happens in the doctor's office.

Ms. Spence further elaborates that she does not think the majority of young women do breast self-exams or any kind of screening for potential symptoms. What she has heard from some women is that they don't know what they are looking for when they do the breast self-exams. On the other hand, she has heard some women say that, if they don't have family history or associated risk factors, it is just not something they are looking out for. The discussion of risk factors is very important, but Ms. Spence cautioned that we don't want to inadvertently send the signal that women without risk factors should not also be looking out for symptoms and engaging in breast self-exams.

The conversation about providers is very important. Ms. Spence has talked to women who have been told by their provider that it is probably nothing. Her thought is that it's not just gaslighting. In instances where the patient has a good relationship with the provider, they might hear the words of "it's probably nothing." What's important is for the messaging from providers to change. Providers should convey to patients that it is probably nothing, but don't delay testing because the consequences of it being something are just too high.

Ms. Spence's second comment for the committee was that she would like to see all workgroups focus specifically on metastatic breast cancer. It is known that young women are more likely to be metastatic de novo, but we also know that treatments are changing, so the protocol might be different if a person is metastatic. One of the issues

that needs to be explored is when should the health care provider go looking for metastases. Questions about survivorship among metastatic patients are growing more important now that patients are living longer. This leads to questions about what it means to have an incurable disease that is effectively a disability, for decades, while trying to have a family and career. It is important for providers to begin discussing what it means in terms of treatment for the patient's life.

The second public comment is from Dr. Diana Zuckerman (see Appendix C: Dr. Diana Zuckerman Full Oral Statement):

Dr. Diana Zuckerman is president of the National Center for Health Research, a nonprofit research center. The center's largest program is focused on cancer prevention and treatment. She previously worked at the White House Office of Science and Technology Policy, HHS, Congress, Harvard, and Yale. She is also a breast cancer survivor. Research shows that young breast cancer survivors are more afraid of recurrence than older survivors, so fear was the focus of her comment. What can be done to help reduce that fear, so that young women have awareness and are educated about their risks and their prevention and treatment options?

Despite the fear, very few women know that diet and exercise help prevent breast cancer and recurrence. Alcohol consumption is an issue, and Dr. Zuckerman also believes that young women should be educated on the links between cancer and ultra-processed foods. Having overweight or obesity increases the risk of breast cancer and of reoccurrence. It is important to educate young women about making favorable lifestyle changes. Many more women undergo mastectomies and bilateral mastectomies in the United States than most other countries. Yet research shows that women who undergo lumpectomy and radiation live longer, with a better quality of life than mastectomy patients.

A new study of more than 23,000 young women with early-stage breast cancer found that the 10-year survival rate was at least as good for lumpectomy as for mastectomy. Research is needed to see how this finding varies among women with specific demographic traits and other risk factors. Dr. Zuckerman suggested that young women be educated on the difference between lifetime risk of breast cancer and their annual risk of developing breast cancer, as well as on ductal carcinoma in situ and invasive breast cancer. The idea is to equip young women with what they need to reduce their fear and to advocate for themselves based on the information they need to make the treatment decisions that are best for them. In her final thought, Dr. Zuckerman asked if CDC can do some kind of educational campaign to make that happen.

Summary and Closing

Speaker: Cristina M. Checka, MD
The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

Dr. Checka acknowledged all of the important and valuable discussion that took place during the meeting. She also thanked everyone, in particular the two public commenters. They both gave fantastic summaries and a challenge to all members as they move forward in their work. Dr. Checka offered another challenge to the group: she asked that they spend 5 to 15 minutes after the meeting writing down their impressions, thoughts, and questions while they were fresh in their mind because the work will have to be divided up, and members will have to divide themselves into workgroups.

Dr. Checka expressed that she was very impressed by the challenges that were posed by committee members to underpin the themes they must hold themselves accountable to address. The way workgroups typically function is that people will typically go where their interest lies, so the hope is that each person's efforts translate into a natural energy, enthusiasm, and momentum. There may also be times where members are called upon to fill in gaps. Dr. Checka concluded by expressing her enthusiasm to work together.

Ms. Smith thanked everyone for an excellent and productive meeting. She continued by thanking everyone for their service and participation on the committee and expressed that she is looking forward to future contributions. She stated that she and Dr. Checka will follow up with next steps and plan for the next meeting by email. In the meantime, members can assign themselves to workgroups and begin working. Ms. Smith acknowledged that since at least one member had concerns about renaming the Sexual Health and Fertility Workgroup to the Reproductive Health Workgroup, this is something that can continue to be discussed. When the full committee meets again, if there is a motion to vote on the name again, it can be done at that time. Before concluding the meeting, Ms. Smith thanked everyone for their time and bid them a great rest of their day.

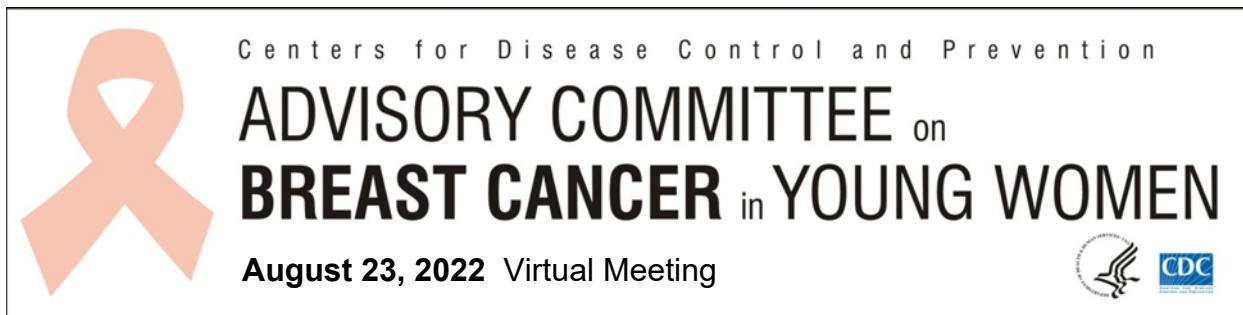
With no further comments, the meeting adjourned at 3:54 p.m. EST.

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

Date

Cristina M. Checka, MD, Chair
Advisory Committee on Breast
Cancer in Young Women

Appendix A: Meeting Agenda



Meeting Objectives

To advise the Secretary of the US Department of Health and Human Services and the Director of the Centers for Disease Control and Prevention regarding the formative research, development, implementation, and evaluation of evidence-based activities designed to prevent breast cancer in young women (particularly among those at heightened risk).

Note: All times are in Eastern Standard Time.

Tuesday, August 23, 2022

11:00 A.M. – 11:30 A.M.

Opening: Welcome, Roll Call, and Introductions

Kimberly E. Smith, MBA, MHA
Designated Federal Officer
CDC, Division of Cancer Prevention and Control

Lisa C. Richardson, MD, MPH
Director
CDC, Division of Cancer Prevention and Control

Cristina M. Checka, MD
The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

11:30 A.M. – 11:45 A.M.	CDC Updates <i>Stephanie Melillo, MPH</i> Health Scientist CDC, Division of Cancer Prevention and Control
11:45 A.M. – 12:30 P.M.	Opening Presentation <i>Cristina M. Checka, MD</i> The University of Texas MD Anderson Cancer Center ACBCYW Committee Chair
12:30 P.M. – 12:40 P.M.	Break
12:40 P.M. – 1:30 P.M.	Presentation: Cured into Destitution: Financial Toxicity in Breast Cancer <i>Anaeze C. Offodile II, MD, MPH</i> The University of Texas MD Anderson Cancer Center Assistant Professor, Department of Plastic Surgery, Division of Surgery Executive Director, Clinical Transformation, Division of Office of the Chief Medical Executive
1:30 P.M. – 2:00 P.M.	Break
2:00 P.M. – 3:30 P.M.	ACBCYW Open Discussion <i>Cristina M. Checka, MD</i> The University of Texas MD Anderson Cancer Center ACBCYW Committee Chair
3:30 P.M. – 3:45 P.M.	Public Comment
3:45 P.M. – 4:00 P.M.	Summary and Closing <i>Cristina M. Checka, MD</i> The University of Texas MD Anderson Cancer Center ACBCYW Committee Chair

Appendix B: ACBCYW Public Roster



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Appendix C: Dr. Diana Zuckerman Full Oral Statement



**NATIONAL CENTER FOR
HEALTH RESEARCH**
The Voice For Prevention, Treatment And Policy

Statement of Dr. Diana Zuckerman

Advisory Committee on Breast Cancer in Young Women

August 23, 2022

I'm pleased to have the opportunity to provide this statement on behalf of the National Center for Health Research. We are a nonprofit research center, and our largest program is focused on cancer prevention and treatment. I previously worked at the White House Office of Science and Technology Policy, the US Department of Health and Human Services, the US House and Senate, Harvard, and Yale. I am also a breast cancer survivor.

Today I want to mention an issue that hasn't been talked about: fear. Research shows that many young women are disproportionately afraid of breast cancer and that young breast cancer survivors are more afraid of recurrence than older survivors. I encourage you to think of what we can do together to help reduce that fear so that young women don't let their fear overwhelm them as they become aware of and educated about their risks, as well as their prevention and treatment options.

Despite their fear, few women of any age know that diet and exercise help prevent breast cancer. You've heard today that alcohol increases the risk of breast cancer, but did you know that drinking more than 3 alcoholic beverages per week can raise the risk of breast cancer? We all know young women who drink much more than that. We should also educate young women about the link between cancer and ultra-processed foods—I'm not just talking about the usual culprits; I'm talking about sauces and many other prepared foods that we assume are healthy when we buy them at the supermarket. In addition, being overweight or obese also increases the risk of breast cancer and of recurrence, because fat cells make more estrogen. We should be educating young women about these strategies for reducing their risks, since these are changes they can control.

Research shows that more women undergo mastectomies and bilateral mastectomies in the United States than most comparable countries. And yet, research shows that early-stage breast cancer patients who undergo lumpectomy (BCT) and radiation live longer with better quality of life than early-stage mastectomy patients, and a study of more than 23,000 young women with early-stage breast cancer found that the 10-year survival rate was at least as good for BCT plus radiation as for mastectomy. Research is needed to see how outcomes vary among women with specific demographic traits and risk factors, but the research available thus far is

reassuring. On a personal note, as a professional in the field, I was shocked when my breast surgeon repeatedly urged me to consider a bilateral mastectomy for Stage 1 breast cancer. I had heard from many other women who had similar experiences. I am sure women who aren't experts in the field, and especially young women, are being influenced by that kind of pressure.

In addition to all the other important issues raised by this committee today, I want to add that we should make sure that young women understand the difference between lifetime risk of breast cancer and their annual risk of developing breast cancer. And the difference between DCIS and invasive breast cancer. Educating young women can help reduce their fear and help enable them to take the time they need to advocate for themselves based on the information needed to make the treatment decisions that are best for them.

One last suggestion: We've heard many great ideas today about the information that primary care physicians, OB/GYNs, and the public need to know about young women and breast cancer, as well as prevention and treatment strategies. Wouldn't it be great if CDC put together an education campaign on some of these key issues, to be shown on TV so it reaches a large audience?