

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



Advisory Committee on Breast Cancer in Young Women

Hybrid Meeting

September 13, 2024

Record of the Proceedings

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ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN

HYBRID MEETING

SEPTEMBER 13, 2024

MINUTES OF THE MEETING

The U.S. Department of Health and Human Services (HHS) and the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control (DCPC), convened the hybrid meeting of the Advisory Committee on Breast Cancer in Young Women (ACBCYW) on September 13, 2024.

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 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

Kimberly E. Smith, MBA, MHA

Designated Federal Officer
CDC, Division of Cancer Prevention and Control

Ms. Kimberly Smith welcomed the participants to the meeting and thanked the committee members for their time and commitment. Members of the public were also welcomed, thanked for their interest, and reminded that prior to 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. She conducted roll call and confirmed 13 voting members, ex-officio members (or their proxies), or liaison representatives in attendance. This constituted a quorum for ACBCYW to continue with the meeting on Friday, September 13, 2024. Jennifer Rose Klemp, PhD, MPH, MA declared a conflict of interest with Caris Life Sciences for the Genetics and Genomics Workshop, as noted in the published agenda ([Appendix A: Published Meeting Agenda](#)). The Committee Chair, Cristina M. Checka, MD, acknowledged the conflict and deemed it acceptable.

Cristina M. Checka, MD

The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

Dr. Cristina Checka welcomed everyone and shared she is pleased to serve as chair of the ACBCYW Committee. She expressed how delighted she was to be able to meet in person and let everyone on the phone know they would be included as if they were attending in person. She then opened the floor for members to give a brief introduction ([Appendix B: ACBCYW Public Roster](#)).

Lisa C. Richardson, MD, MPH

Director

CDC, Division of Cancer Prevention and Control

Dr. Lisa Richardson thanked the members of the committee for their service and the breast cancer survivors for sharing their experience. She then provided updates from the Division of Cancer Prevention and Control (DCPC), specifically on the Strategic Priority Framework and its mission, aspirations, strategic priorities, guiding principles, and strengths ([Appendix C: Strategic Priority Framework](#)). Dr. Richardson reminded the committee that the work they do meets the framework's aspirational goals and priorities. The framework is the foundation of setting the stage for the work that needs to be done and at the next meeting, she'll go more in depth on the framework's components and how they are implemented.

Questions and Answers

During the question and answer session, the first question was, "If this framework is also including survivorship, are we looking at what survivorship looks like for the metastatic breast cancer (MBC) community?". It was mentioned there might be a need to include someone from the MBC community. Dr. Richardson agreed, stating that they have a group of people dedicated to working with women with MBC. She also mentioned that caregivers are critical and are also the group that gets left out the most, thus they have to pay better attention to that group.

The second question was, "Did topics around psychosocial support come up as either a guiding principle or one of the priorities across this framework?". Dr. Richardson referenced the strategic priorities section of the framework and highlighted the third one referenced survivors, which allowed them to look at caregivers and what people go through psychologically.

A comment was made by Maimah Karmo, that the committee has launched a mental health committee, and she would be sharing more about the work they're doing.

There was a question, "What role can the CDC play in promoting funding and the academic community to pursue research?". Dr. Richardson replied that DCPC cannot advocate for themselves, as they are the public health arm. Instead, Dr. Richardson wants to see her division evaluating what's already being done to see if it's working. Research is not their primary focus; however, it's important to remember there are lots of needs that aren't focused on drug development that the committee could assist with.

A comment was made by Jasmine Dionne Souers, stating that it's important to consider mental health in the screening area. Dr. Richardson responded that mental health should be considered everywhere across the spectrum of cancer.

There was a question, "Will there be considerations for people with inherited genetic mutations in terms of hereditary cancer and how is that part of those aspirations in terms of survivorship, screening, and prevention?". Dr. Richardson replied that when she says, "all people free of cancer," people often ask, "What about survivors?". She stated that if you have risk genes, you're at risk for other cancers. "All people free of cancer" includes survivors because the risk is there, and so is the focus on risk reduction and prevention.

A comment was made by Ricki Fairley, that she's curious about research on why young women are getting breast cancer, especially Black women, and what factors are driving breast cancer to happen.

Dr. Richardson responded that this gets into organization and funding, and CDC does not receive money to do research; their primary mission is public health and interventions.

Dr. Kisha Coa brought up that there is a White House initiative on women's health research, support, and resources that could be a great opportunity to reach other federal agencies.

There was a question about the wording of the prevention aspirational goal since it's understood that breast cancer is not preventable. Dr. Richardson clarified that prevention is a broad term. For example, mastectomy is prevention, as well as some drugs used to lower risk and prevent cancer, which is why language around reducing risk is included in the framework.

There was a question, "Is this framework specifically for breast cancer?". Dr. Richardson clarified that no, this applies to and informs all of CDC's work in cancer prevention and control.

There was a comment from Ricki Fairley, that when the American Cancer Society's National Breast Cancer Roundtable convened, they focused on the term "risk reduction" because prevention is a contentious word.

CDC Updates

Temeika L. Fairley, PhD

Senior Health Scientist

CDC, Division of Cancer Prevention and Control

Dr. Temeika Fairley started her presentation by giving a brief overview of the Breast Cancer Education and Awareness Requires Learning Young (EARLY) Act. CDC was mandated to increase awareness of early-onset breast cancer (EOBC) among young women and health care providers. Dr. Fairley discussed updates from CDC on health care provider education component of this requirement.

Dr. Fairley discussed CDC's efforts, highlighting that in 2017 and 2020, CDC launched some 1-credit CME opportunities for health care providers that resulted in 15,000 learners participating with 11,000 CME credits and 7,000 CME certificates issued. She also highlighted several CDC-funded efforts in medical education, including virtual and in person trainings, a CME training course on topics related to hereditary breast and ovarian cancer (HBOC) such as diagnosis, survivorship, patient-provider communication, financial impacts, risk management, and cultural competency.

Dr. Fairley spent the remainder of the presentation discussing a collaboration with the American College of Obstetricians and Gynecologists (ACOG). She outlined the activities involved in the project, which involved convening expert and stakeholder panels, conducting literature reviews, developing peer reviewed publications, and developing two 7-credit EOBC e-modules, which are hosted on the ACOG website. Paid media ads and in-person visits to medical society meetings were among the marketing strategies used for outreach and dissemination. Metrics for EOBC trainings show 5,087 registrations, 4,271 course completions, 21,357 CME credits awarded, and 1,477 nursing CEU credits awarded.

In terms of next steps, CDC would like to reach audiences of health professions students, health care plans, and provider insurance, in accordance with prior Committee recommendations. CDC is looking to the committee for guidance on whether these are still relevant audiences. Reaching health care providers through systems-level changes is the focus going forward. Dr. Fairley concluded by stating that she eagerly anticipates the committee's recommendations.

Questions and Answers

There was a question about how to approach adding training to the curriculum when students are taught in a manner that "teaches to the test." Dr. Fairley replied that they are now thinking about how they can get to the people who are writing the tests, such as licensing boards and accrediting bodies, since the tests are driving the curriculum.

A comment was made about electronic health records (EHR) and how there's an opportunity to build education into these systems, followed by a comment about the role of insurance, specifically the steps

providers need to go through when testing is denied and how beneficial it could be to help providers know how to code correctly.

Dr. Fairley responded that they have not been successful moving into the EHR world either and it continues to be a struggle. They had not thought about coding before, so Dr. Fairley is interested to hear recommendations from the workgroup has around this topic.

There was a comment that surgical societies weren't noted as part of the collaborative groups, and the recommendation was made to engage with the American College of Surgeons, as well as integrating through UpToDate in addition to Medscape for CME credits.

There was a comment about frustrations caused by crosswalks of accreditation having different names and timelines, and the need to align on guidelines.

There was a question, "Did you see that the interest in trainings matched up with the topics that were most prevalent?". Dr. Fairley replied that those topics were not at the top of the list, which is why patient-provider communication is so important, as well as diligently approaching this issue from both sides.

There was a comment that patient care coordinators are a good target audience because they're talking to patients about critical issues and are the bridge between providers and patients.

Ally Moehring

Health Communication Specialist
CDC, Division of Cancer Prevention and Control

Ms. Ally Moehring began by briefly introducing herself, then gave an overview of the *Bring Your Brave* campaign, emphasizing how the stories of young survivors and previvors are the backbone of this campaign to raise awareness. The campaign is now evolving to leverage those stories so survivors and previvors are speaking to each other to address feelings of isolation.

Ms. Moehring presented the campaign's latest content and shared how it focuses heavily on high risk and family history, encouraging people to look at the full picture of their family's history with cancer. The campaign's messaging also supports caregivers and talks to women directly about how to ask for help.

The following videos were shown:

- **Beyond the Diagnosis: Family Planning:** Unscripted roundtable conversations among survivors and previvors discussing topics like intimacy, relationships, body image, family planning, and living with stage 4 MBC.
- **Being a Previvor:** How previvors experience judgement and a lack of understanding from their existing support systems.
- **Carletta: Survivor Guilt:** How a story can change after 10 years of survivorship.
- **Supporting Survivors: Sally and Gloria:** Seeking caregivers and supporting young survivors.

Ms. Moehring then discussed the paid media and content partnerships the campaign uses to reach specific audiences in unique ways. She spoke about the ongoing audience research being done, such as recent focus groups with women unaware of their risk, as well as previvors, which was a first for the campaign. She reviewed the campaign's work educating through TV and gaming; the proactive process to inform, encourage, and excite writers about the importance of sharing information; the reactive process of serving as advisors to writers; and the goals of infusing storylines with facts, improving accuracy and representation, dispelling myths, and encouraging sensitive, realistic portrayals. Ms. Moehring also highlighted specific entertainment that featured the campaign's storylines, such as the TV shows *Superman & Lois* and *All American: Homecoming*. The campaign is talking to a gaming company to

integrate storylines into mobile games, and producers in the unscripted television space about accurately and responsibly talking about breast cancer.

Questions and Answers

During the question and answer session, the first question was, “For the young healthy population, not the previvors, not the genetically at-risk folks—so the largest percentage of women—is the entertainment the main focus for how you reach them through the storylines or do you have any other dedicated outreach that is just meant for the 20-something who is not thinking of breast cancer at all?”. Ms. Moehring replied that it’s all of the above: the unaware audience has not been neglected. The campaign has videos coming out around signs and symptoms.

A follow-up question was asked about quantifying impact. “Are there any other tips you have for people that could also do work in the space to be creative with using data in order to support the impact of the work we’re doing?” Ms. Moehring responded by saying that’s what the campaign is always trying to chase—how to quantify moving the needle. Entertainment education is more tangible because you can look at when the episode aired and the website visit spikes that follow. With the other work, webpage visits, engagement, and impressions are the metrics being tracked. They’re always looking at ways to evaluate how things are working because this can be hard to quantify.

A comment was made about how breast cancer is different in the Black community and the need to have a broader audience in this community.

There was a question about the amount of money spent on the campaign. Ms. Moehring replied that she would have to go back and look at the numbers—she didn’t have them off the top of her head—but the budget is not enormous, and they have to be very mindful about where they’re putting their dollars.

A question was asked relating to poor expectation management regarding fertility in general. “How do you build on maybe rightsizing some of that information that’s already out there, or how do we set better expectations, and how do we script it so we don’t have to reteach every care team about how to have these discussions?” Ms. Moehring replied that survivors report they’re angry because no one told them this was going to affect their fertility.

Updates from the Field

Ricki Fairley, MBA

Chief Executive Officer

TOUCH, The Black Breast Cancer Alliance

Ms. Ricki Fairley began by sharing her journey from a stage 3 triple-negative breast cancer (TNBC) diagnosis to becoming an advocate. She then highlighted the disproportionate impact of breast cancer on young Black women, who have a 41% higher mortality rate and 39% higher recurrence rate compared to White women, and it’s not known why. The physiology of Black women has not been a consideration in clinical trial research. Ms. Fairley shared how she coined the term “Black Breast Cancer,” which she defines as the constellation of exposures, experiences, and lack of science for Black women diagnosed with breast cancer that causes Black women to face disproportionately worse breast cancer outcomes.

Ms. Fairley’s organization, TOUCH, focuses on clinical trials, young women and risk assessment, storytelling, providing resources, strategic partnership, and support groups in their mission to eradicate Black breast cancer. The organization reaches about 3 million people per year, makes a lot of media impressions, and tries to be in the community by throwing an event almost every weekend to engage with women where they are. She highlighted one of their biggest media platforms, *The Doctor Is In*, a web series in partnership with BlackDoctor.org that airs live every Wednesday at 6pm Eastern Time.

Ms. Fairley discussed marketing research being done to understand why Black women don’t participate in clinical trials. They learned that doctors don’t invite Black women to clinical trials and that Black women

don't understand what a clinical trial is. Their *When We Tri(al)* campaign to talk to women about clinical trials is working. In the past 2 years, 19,453 Black women have signed up to participate in clinical trials.

Ms. Fairley shared that the organization established a 24/7 hotline for navigation and began helping pharmaceutical companies write their material to recruit women, explaining trials in ways Black women can understand. Having this navigation support increased trial participation from 13% to 41%.

Ms. Fairley also shared about the campaign, *For the Love of My Gurls*, which targets healthy women ages 18 to 35—a group that gets breast cancer at twice the rate of White women and dies at three times the rate. The campaign has reached more than 850,000 people and touched nearly 85,000 people. Their show, *Pink Table Talk*, has reached more than 225,000 viewers.

Ms. Fairley shared that the BELONG (Blessties Empowering Leadership, Opportunity, and Nurturing Growth) campaign, started this year, recruits women who support other women. It is now in 43 states, Canada, and the United Kingdom, and hosts a monthly webinar disseminating medical information from a doctor on their advisory board.

Ms. Fairley ended by announcing that in November, the organization will launch a website dedicated to supporting women through their journey with TNBC. Additionally, they are participating in the Cancer Grand Challenge, which studies social determinants of health, genetics, genomics, and epigenetics across various cancers worldwide. They have also partnered with BlackDoctor.org on the *Sambai Speaks* initiative to recruit viewers in Africa to explore how this research will affect their communities.

Questions and Answers

The first question was, “The trials focus is so powerful. Have you or others thought of taking this to other cancers or others using this model to try and increase diversity in trial situations for other areas?” Ms. Fairley answered that everyone should use it because it's working and it's so simple. They are doing it with heart disease and prostate cancer. A free training program that takes 30 minutes to teach how the tools work can be downloaded from their website.

A question was posed around increasing diversity in trials and how TOUCH can support investigators. Ms. Fairley replied they have a video for investigators discussing how the organization works and is designed to help them recruit. This video can be provided to those who want it.

Verinda Hobbs

Partnership Strategy Manager
FORCE: Facing Hereditary Cancer Empowered

Ms. Verinda Hobbs began by sharing information about FORCE programs and resources to support young people with, or at high risk for, breast cancer. She introduced the organization, which supports people with inherited mutations linked to cancer.

She presented results from a 2024 needs assessment survey of female, non-binary, or transgender people ages 18 to 45 who are at high risk for breast and gynecologic cancers. In total, 1,261 people responded, and for this presentation, the results of 328 people were shared. They found that about 2/3 of the respondents had a BRCA1 or BRCA2 gene mutation.

Ms. Hobbs discussed genetic testing, risk management, and previvorship, and how FORCE coined the term “previvor” to provide a label for an important high-risk group: those living with an elevated risk for cancer who have not been diagnosed with cancer, and in many cases, have very similar issues navigating the health system.

She presented guidelines for breast cancer risk management, specifically for BRCA1 and BRCA2, and highlighted the barriers for this population given that the guidelines recommend screening beginning at age 25, which is different than the screening recommendations for the average woman. She spoke about guideline recommendations around the removal of ovaries and Fallopian tubes: how the recommendation

is before the age of natural menopause, the extreme side effects associated with this, and the use of hormone replacement therapy after risk-reducing salpingo-oophorectomy, highlighting that for women who have not had breast cancer, the benefits of hormone replacement therapy outweigh the risk.

Ms. Hobbs then focused on barriers to breast screening, stating that half of respondents found it hard to prepare emotionally for their screening or the results of those screenings; about 1/5 found it hard to find a facility that had experience serving high-risk people, and almost 1/4 found it hard to pay for the recommended breast screening. She went on to discuss risk-reducing mastectomies, reporting that 57% of respondents had completed or were in the process of having a risk-reducing double mastectomy, and the barriers associated with those procedures, highlighting that respondents found the process extremely hard emotionally, physically, and financially. Ms. Hobbs discussed the burdens of risk management, emphasizing the challenges she previously spoke about and how respondents reported that medical advice is inconsistent with the guidelines.

Ms. Hobbs discussed breast cancer risk management research and pointed out that members of their community are very interested in participating in prevention research studies, but most have never had a health care professional mention participating, and most do not know how to find prevention studies enrolling people with inherited mutations.

In terms of caregiving and family, respondents reported a large hereditary cancer caregiver burden. More than half of respondents had cared for a relative with cancer, reporting instances of multigenerational trauma, caregiving beginning at young ages, gaps for caregiver information and support, and having to provide caregiving at the same time they were navigating their own diagnosis.

Ms. Hobbs discussed the FORCE programs that help address the needs of young survivors and providers, talking briefly about how many respondents received conflicting information about their medical options, and how FORCE provides expert-reviewed information, individual guidelines on hereditary breast cancer, and information on high-priority topics.

Ms. Hobbs spoke about FORCE's XRAY (eXamining the Relevance of Articles for You) program that provides plain-language summaries of relevant research, debunking the media hype often found in research taken out of context. She spoke about the dedicated resources and initiatives for previvors, including emotional support from peers, 1-on-1 navigation from peers, and navigation to health care experts and services.

Ms. Hobbs noted their community is very interested in participating in research; however, most have never been told about studies by their health care team or don't know how to find a study relevant to their situation. She spoke about FORCE's research search and enroll tool, a custom database of studies enrolling people with inherited mutations.

She touched on state laws on insurance coverage for breast cancer screening, that paying for care is often a barrier to screening and prevention, and how FORCE educates people on state screening laws. She spoke about resources that provide sample appeal letters and links to programs and partners that offer financial assistance.

Ms. Hobbs concluded her presentation by highlighting some of their 81 partners. More than half of them focus on breast cancer and 1/4 focus on inclusion and health equity.

Samantha Lynn Heller, PhD, MD, FSBI

Associate Professor of Radiology
Perlmutter Cancer Center
New York University School of Medicine

Dr. Samantha Heller began her presentation on the challenges and opportunities that come with imaging young women with breast cancer by highlighting that breast cancer is a leading cause of cancer death in young women, with incidence increasing and young age being a risk factor for a poor prognosis. Young patients face more aggressive tumors and a higher risk of recurrence.

The presentation focused on breast cancer detection, particularly imaging tools for those with a known high risk and for young women with unknown risk. Dr. Heller detailed the perfect breast cancer screening test as one that detects disease early, is inexpensive, easy to administer, specific, sensitive, tolerable, safe, improves outcomes, and decreases mortality. Key imaging tools discussed include mammography, ultrasound, and MRI.

Mammography is effective in improving outcomes and reducing mortality; however, it has limitations in detecting cancer in dense breasts, which is more common in younger women. Density can mask cancers, making detection difficult despite advances like digital mammography and tomosynthesis.

Ultrasound is commonly used, relatively inexpensive, and available, and can find additional cancers, especially invasive ones. But it has limitations such as operator dependency, higher false positives, and lack of strong evidence on mortality reduction.

MRI is the most sensitive tool available for finding cancers. It decreases advanced-stage breast cancer incidence in high-risk women and offers longer survival in populations with high-risk family history and genetic mutations. While MRI is now considered the “workhorse” for high-risk screening, it has lower specificity compared to mammography and is expensive, time-consuming, and uncomfortable for patients. Additionally, access to MRI machines is limited in many parts of the world.

Dr. Heller spoke about how radiology is working to shorten MRI exam times and make them more tolerable and cost-effective. Techniques like abbreviated MRI exams and ultra-fast MRI, which focus on early time points in the imaging process, have shown promise in reducing the duration of the scan without sacrificing accuracy. These techniques aim to make MRI more accessible and easier for patients.

Dr. Heller spoke about the use of artificial intelligence (AI) in detection and how AI is being increasingly integrated into mammogram analysis to help flag potential cancers. For instance, a homegrown AI model flagged cancers that might have otherwise gone unnoticed, particularly in dense breast tissue. However, there’s a need to ensure that these models work effectively across diverse populations.

Dr. Heller then spoke about young women with unknown risk, highlighting diagnostic presentation as a key point in populations that would normally not be screened for breast cancer and that you wouldn’t know to screen. Dr. Heller spoke about pregnancy-associated breast cancer and how late presentation and incidence are increasing in this population. She then went on to dispel common myths around mammography during pregnancy and lactation: there’s no contraindication for mammography without contrast during pregnancy and lactation.

Dr. Heller reiterated the points of discussion that young women under age 40 without identifiable risk factors do not undergo screening, and most women with breast cancer do not have a known family history of breast cancer or a genetic mutation. She raised the question of starting screening and imaging at a younger age, highlighting that from an imaging perspective, the available tools are not effective for a large-scale population. She then touched on global disparities in breast cancer screening and treatment.

Dr. Heller concluded her presentation by highlighting emerging areas of interest, including using AI to predict cancer risk from imaging alone, potentially allowing for more personalized screening pathways. Other areas include integrating imaging with liquid biopsy techniques and improving the overall screening experience, as well as access to screening, addressing anxiety associated with repeated screenings, and increasing awareness of the potential for breast cancer in young women with symptoms, including in pregnancy and the peripartum period.

ACBCYW Workgroup Reports and Open Discussion

Cristina M. Checka, MD

The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

Dr. Cristina Checka introduced the next items on the agenda: the committee workgroup presentations. She noted the committee's work is centered in four workgroups, and that updates will be provided in the following order: **Provider and Healthcare Systems Workgroup**, **Reproductive Health Workgroup**, **Genetics and Genomics Workgroup**, and **Mental Health Workgroup**. Dr. Checka reminded the committee that they are welcome to serve on more than one workgroup.

Provider and Healthcare Systems Workgroup

Dr. Samantha Heller began her presentation by sharing that the workgroup ideas are divided into different buckets, with the first being early risk assessment.

Bucket 1: Under the early risk assessment bucket, Dr. Heller shared these ideas:

- Promote a national campaign for early risk assessment.
- Promote understanding of factors contributing to increased risk of breast cancer in adolescent and young adult women.
- Identify genetic links sooner.
- Promote understanding of mutations, including and in addition to BRCA, that confer an increased risk of breast cancer.
- Include resources for Black and indigenous people of color (BIPOC) women and rural communities.
- Address cultural issues that may prevent women from acting even when educated.

Bucket 2: Under the education in terms of improving provider awareness bucket, Dr. Heller shared these ideas:

- Provide data-driven updates regarding rising incidence of breast cancer in young women, disease presentation in young women, and incidence in young women without known genetic mutations.
- Make providers aware of the difficulties young women face seeking a prompt diagnosis and address provider bias.
- Consider focusing education and resources by type of provider (develop in partnership with patients for maximum patient-friendly and effective materials):
 - Primary care physicians (largest impact and greatest focus)
 - Obstetricians and gynecologists
 - Radiologists
 - Pediatricians
 - Breast surgeons
 - Oncologists
 - Reconstruction and plastic surgeons
 - Genetic counselors
 - Nurse navigators
 - Mid-level providers such as nurse practitioners and physician assistants

Bucket 3: Under the education in terms of patient awareness bucket, Dr. Heller shared these ideas:

- Improve education regarding signs, symptoms, and risks of breast cancer.
- Examine resources for awareness of breast cancer, particularly parents, physicians, schools (high school sex ed curriculum), colleges, public health groups, and student activity groups.

- Additional potential resources include middle school, sororities, mother and daughter groups, community advocacy groups, and authors of books about puberty and health.

Bucket 4: Under resources to address barriers to breast cancer prevention, diagnosis, and treatment, Dr. Heller shared these ideas:

- Identify social determinants of health.
- Identify potential barriers to care.
- Identify resources to overcome barriers to care as well as ways to reach populations at high risk for cancer and for poorer outcomes.

Bucket 5: Under screening in pregnancy and lactation, Dr. Heller shared these ideas:

- **Background:** Persistent widespread confusion about screening in this setting.
- **Goal:** Dispel common misconceptions about the safety of mammography during pregnancy.
- Provide clear recommendations for patients and providers regarding modality-specific screening recommendations during lactation and pregnancy.

Bucket 6: Under resources for reconstruction, Dr. Heller shared these ideas:

- Opportunities to support access to deep inferior epigastric perforator (DIEP) flap reconstruction.
- In a major step forward in the effort to preserve access to microsurgical breast reconstruction, the Centers of Medicare & Medicaid Services (CMS) announced on August 21, 2023 that it would maintain HCPCS level II codes S2066, S2067, and S2068 covering DIEP, GAP, and SIEA flaps.

Dr. Michael Howard clarified the nuances surrounding the medical coding of microsurgical breast reconstruction. He began by stating that there are two ways to reconstruct breasts following mastectomy: implant-based reconstruction, and own tissue (or autologous) reconstruction. Implant-based reconstruction is very common and widely used across the United States. Autologous reconstruction is more specialized and used less often. The codes Dr. Heller referred to are how surgeons bill and document the surgery performed. While surgeons like permanent codes, these codes are temporary in the coding literature. When this surgery was developed about 15 years ago, it couldn't get a permanent code because it was new. The temporary codes are supposed to be used for only 2 or 3 years and then be replaced with permanent codes, but these have remained for 10 to 15 years. Insurance companies tried to get surgeons to stop using temporary codes and put all of these specialized reconstructions under generic plastic surgery codes. While that makes some sense, it would bring a host of problems from an insurance billing and coverage standpoint and potentially decrease reimbursements for the specialized surgery, which would mean fewer autologous surgeries performed and women would lose out. Fortunately, there was a lot of outcry and the insurance companies backed off.

Dr. Howard also highlighted regional differences the committee members are seeing, indicating that financial differences—especially the rate at which insurance carriers are reimbursing for these procedures—is one of those areas. Unfortunately, that drives some people's decisions. He reiterated that it's unfortunate, but sometimes state budgets dictate health care decision-making.

A question was asked about how to factor in the cost of the follow-ups and imaging many survivors will need for the rest of their lives. Dr. Heller replied that was a deliberate omission in terms of not having the time to address every concern in this area. She added that when it comes to post-diagnosis surveillance, data can be lacking because many randomized controlled trials look at average-risk women.

There was a comment that there is also variability in subtype, and the question of whether there's a need to incorporate MRI into every post-lumpectomy patient. It was noted that there's a lot of variability among all of the interests of the committee, as well as a lot of questions that still need to be asked and answered.

Another comment was made that when you start looking at how high the recurrence rates are in the subpopulation the committee is focused on, it might not be unreasonable for certain subtypes to have full body imaging; however, that's very variable across regions. Dr. Heller replied that on the radiology side, there is a lot of focus on second cancers presenting between screens and what factors might precipitate someone to be at higher risk and need a more intense surveillance regimen.

Another comment was made that the insurance piece is an important part of this conversation.

Dr. Heller continued her presentation.

Bucket 7: Under long-term support, Dr. Heller shared these ideas:

- **Ongoing treatment:** Resources for survivors to keep up with new advances that might be beneficial for screening and proactive breast health after the acute treatment phase is past.
- Resources for caregivers and to address caregivers' needs.

Bucket 8: Under narratives, Dr. Heller shared these ideas:

- Sharing stories and narratives which may encourage awareness for both patients and providers. See *Bring Your Brave* and ensure representation and a wide range of stories (for examples, no metastatic disease narratives now).
- Engage patient influencers to promote the program or campaign, such as previvor influencers.

Bucket 9: Under mental health support, Dr. Heller shared that this topic is cross-cutting with the Mental/Behavioral Health Workgroup:

Questions and Answers

A question was asked, "Have survivorship care plans really fallen by the wayside? And is there a place for including additional recommendations around making sure that people are getting survivorship care plans so they know what to look for down the road after they've been released from their oncologists?". Dr. Anne Blaes addressed the question by stating that CDC had a call out recently for funding mechanisms to look at the effect of survivorship care plans on outcomes. Those announcements just came out and she could provide an update down the road. She also noted that in the last year, the National Cancer Institute came up with a set of standards around survivorship care. The updated standards provide a more comprehensive look at survivorship care. Dr. Jennifer Rose Klemp also responded by stating that the care plan is now a tool and is no longer considered the gold standard.

A comment was made by a committee member who is a long-term survivor of EOBC and was recently diagnosed with aggressive thyroid cancer, which is believed to be a result of the aggressive radiation on her clavicular chain. Radiation is a known cause of thyroid cancer, and that was never communicated to her after her treatment. This is an example of how people feel like the rug is being pulled out from under them after they're released from their oncologist's care.

Another comment was made that the recent CMS expansion from November 2023 for how navigation will be reimbursed also has an effect because navigation may also take up the mantle of survivorship care, which goes on for many decades. Dr. Klemp added that it's essential to use the reimbursements being offered even though they're nominal because you won't get more if you don't use it, and the only way to get more is to show continuity of care is improving.

Dr. Checka stated that at present, nothing from this workgroup needs to be voted on, and asked Dr. Heller if she felt that the workgroup was making progress toward a final list of recommendations, perhaps by the next meeting in 2025. Dr. Heller replied that yes, that would be a good goal.

Reproductive Health Workgroup

Ms. Arin Ahlum Hanson began by giving a brief history of the workgroup, stating they do not have formal recommendations to be voted on, and shared that the workgroup is recruiting more members. Ms. Hanson stated the purpose of the workgroup: to provide the ACBCYW committee with an overview of current issues in sexual health, including resource gaps, and evidence-based interventions of young women facing breast cancer. She also stated their goals: to improve collaboration and documentation toward acknowledgment, assessment, and interventions offered for reproductive and sexual health concerns in young women with breast cancer, and offer recommendations to improve value and service for the ACBCYW.

Ms. Hanson shared the complex unmet needs and gaps in care, such as:

- Oncofertility and fertility preservation.
- Pregnancy after breast cancer.
- Sexual health concerns.
- Body image.
- Decisional regret.
- Libido.
- Relationship image.
- Diversity and inclusion of resources for LGBTQ patients.
- Fear of recurrence.
- Provider education and comfort with topic.
- Financial toxicity of treatment options.
- Metastatic community needs.
- Endocrine medication adherence.
- Culture and taboos around sexuality.
- Misinformation.

Ms. Hanson stated that the discussion today would focus on the first three topics mentioned.

In terms of fertility preservation and access to fertility preservation and iatrogenic infertility treatments, Ms. Hanson shared these ideas:

- Fertility preservation, storage, and transfer procedures are very expensive, and the majority of young breast cancer survivors do not have insurance coverage.
- Insurance coverage is improving for fertility services (Kaiser Family Foundation).
- Some needs assessments show that fertility is a top concern for young breast cancer survivors.
- Recent personhood bills and abortion bans are affecting the reproductive care of young breast cancer survivors in some states.

Ms. Hanson highlighted the 19 states with fertility preservation coverage and noted there's a lot of variation in coverage in each state.

In terms of fertility preservation recommendations, Ms. Hanson shared these ideas:

- Committee to advocate for fertility preservation to be considered a medically necessary part of treatment for young breast cancer survivors and a standard of care.

- Request that CDC research how fertility preservation affects young breast cancer survivors' finances and quality of life.
- Request that CDC develop interventions to help young breast cancer survivors make decisions about fertility preservation.

There was a comment recognizing this is something that's still not covered for a lot of survivors and that there's a real unmet need for survivors to have access to fertility preservation. A second comment was made echoing this sentiment and emphasizing the potential effect of screening for genetic mutations in the fertility process. A third comment mentioned that in addition to the issue of financial accessibility, there's the issue of living in a state that's had recent legislation change, with Dr. Brooke Vuong noting that legislation varies widely from state to state.

Another committee member made a final comment recounting her personal experience with freezing her eggs and how costly the process was for a 30% chance, which did not feel like a win for her at the time.

Dr. Brooke Vuong then presented on pregnancy after breast cancer, discussing the results of the Interrupting Endocrine Therapy to Attempt Pregnancy after Breast Cancer (POSITIVE Trial) that were published in the *New England Journal of Medicine* in May 2023. She shared the following information:

- December 2014 to 2019
- Median time from diagnosis to enrollment: 29 months
- Median age: 37 years
- 497 patients with hormone receptor positive (HR+) breast cancer
 - Stage 1 through 3 breast cancer
 - 93.4% stage 1 or 2
 - 29.3% had 1 to 3 positive lymph nodes
 - 62% received chemotherapy
 - On endocrine therapy for 18 to 30 months
- Intervention: Stop treatment for as long as 2 years, then complete total 5 to 10 years
- External control: 1,499 patients from SOFT and TEXT

POSITIVE Trial Results

- 44 patients had a breast cancer event
 - Defined as ipsilateral or locoregional invasive disease, distant recurrence, or contralateral invasive breast cancer
 - 3 year incidence was 8.9% (9.2% in external control)
- 22 distant recurrences
 - 3 year distant recurrence 4.5% (5.8% in external control)
- 368 patients had at least one pregnancy
 - 317 had at least one live birth
 - 365 babies were born
- Younger age related to successful pregnancy
 - 85.7% among those younger than 35; 76% among those 25 to 39; 52.7% among those 40 to 42
- 15.4% did not restart endocrine therapy by 48 months
- HR for breast cancer event 0.53 (95% confidence interval, 0.27 to 1.04)
 - No increased risk of breast cancer event associated with pregnancy
- Temporary interruption of endocrine therapy did not appear to have a short-term effect on oncologic outcomes

Dr. Vuong shared that the trial discussion centered on these ideas:

- The percentage of women who became pregnant is higher than general rates of pregnancy in similar age groups, regardless of breast cancer diagnosis.

- Women were enrolled at least 18 months after chemotherapy. Women who conceived within 1 year of chemotherapy had a higher risk of preterm birth.
- Questions arose regarding if this was a result of the “healthy mother effect.”
- Relatively short-term follow-up considering recurrences can occur 20 years later.

Dr. Vuong discussed the secondary analysis of POSITIVE Trial, sharing these ideas:

- 179 patients used embryo or oocyte cryopreservation prior to enrollment.
- 215 used assisted reproductive technology to attempt pregnancy.
 - Ovarian stimulation for invitro fertilization and embryo transfer.
 - 9.7% 3 year recurrence rate with ovarian stimulation; 8.7% without ovarian stimulation.
- Younger age and cryopreserved embryo transfer associated with higher chances of pregnancy.
 - 82.4% became pregnant with embryo transfer.
 - 80% of women younger than 35 became pregnant compared to 50% of those over 40.
- Menstrual cycles returned within 6 months of pausing endocrine therapy.
- The type of endocrine therapy had no effect.
- Demonstrates short-term safety of fertility preservation and assisted reproductive technology.

Dr. Vuong went on to discuss the Pregnancy After Breast Cancer in Young BRCA Carriers: An International Hospital-Based Cohort Study, sharing this information:

- January to December 2020
- 78 centers
- Breast cancer diagnosis at age 40 or younger, all subtypes with BRCA1 and/or BRCA2
- N= 4,732
 - 659 had at least one pregnancy
 - Median age at diagnosis: 35
- Medium follow-up 7.8 years
- 1 in 5 conceived within 10 years of diagnosis
- Majority (79.2%) of the pregnancies occurred spontaneously
- No difference in disease-free survival was observed between patients with or without a pregnancy (aHR 0.99, 95% confidence interval 0.81 to 1.2)
- Patients who had a pregnancy had significantly better breast-cancer specific survival and overall survival.

Dr. Vuong concluded by summarizing the ideas she shared, specifically:

Recent data provides optimistic short-term results about the ability to conceive after pregnancy. Temporary interruption in endocrine therapy (as long as 2 years) does not affect oncologic outcomes. Ovarian stimulation did not appear to affect 3 year recurrence rates. Pregnancy does not appear to affect disease-free survival among BRCA carriers.

Dr. Maryam Lustberg then presented on the topic of sexual concerns. She shared that sexual health affects multiple domains including body image, relationship concerns, physical symptoms, emotional concerns, libido, and safety of hormonal options. She acknowledged that sexuality is a human right as important as ensuring fertility, and that oncology clinicians must open the door for patients to discuss sexuality after cancer.

Dr. Lustberg discussed the range of physical symptoms, sexual concerns, and interventions in young women with breast cancer. She noted the interventions are not perfect. Depending on where a person gets care, these interventions may not be offered or people may not have complete access to them.

Dr. Lustberg spoke about hormonal therapies and how there's been a siloed existence between oncologists and women's health specialists in terms of menopausal hormone therapies. There's been recent media coverage on oncologists not being open to the idea of systemic HRT in certain patient populations. She cited data that informs the decision-making of breast medical oncologists, particularly

surrounding hormonally driven tumors, and how it bears having an open conversation about the pros and cons of systemic HRT in that situation.

Dr. Lustberg then discussed vaginal estrogen, sharing ACOG's opinion, specifically:

- Nonhormonal approaches are the first-line choices during or after treatment for breast cancer.
- Reserve vaginal ERT for women who do not benefit from nonhormonal approaches, and the importance of collaboration and shared decision making.
- Data do not show an increased risk of recurrence after breast cancer with vaginal estrogen.

Dr. Lustberg stated that even with opinions from ACOG and the North American Menopause Society over the last several years, there is still a great deal of hesitancy about the safety of vaginal estrogen, highlighting this as an area of opportunity for additional dialogue in education with patients and clinicians.

Dr. Lustberg cited a Danish Observational Cohort study of patients treated for early-stage breast cancer from 1997 to 2004. A small number of participants who received aromatase inhibitors saw a slightly increased risk of breast cancer recurrence. She highlighted the limitations of the study—the dosing of vaginal estrogen was not disclosed—urging a cautious interpretation. She spoke of another recent study that was not widely publicized. This observational study with a sample size of nearly 50,000 females with a history of breast cancer showed no increased risk of breast cancer for vaginal estrogen users.

Dr. Lustberg discussed how sexual health concerns are approached within the clinic. Several techniques can help patients feel comfortable talking to their clinicians. She concluded the presentation by summarizing the sexual concerns she had spoken about and how there are many opportunities to address sexual health concerns in younger women and educate clinicians. She welcomed suggestions and input for the committee and reminded them this workgroup would like one or two more members.

Questions and Answers

There was a comment about previvors, that there is still a lot of misinformation about the safety of HRT in young previvors who have removed their ovaries, some of whom have also had mastectomies, and there's a lot of room for provider education as well as patient education in those areas. A second comment from Dr. Klemp echoed this concern. She stated that at her high-risk clinic, of the nearly 2,000 new consults they get each year, half come from an obstetricians and gynecologists who ask if it's safe for their patient to take hormones. Dr. Lustberg stated she thought this is an educational—and possibly an editorial—opportunity to put out some type of white paper mythbuster around hormonal therapies.

Genetics and Genomics Workgroup

Ms. Ashley Dedmon shared an overview of what the presentation would focus on, specifically their goals, previous recommendations, proposed recommendations, and critical areas of exploration.

Ms. Dedmon stated the goal of the workgroup was to enhance collaboration and documentation for the assessment and recommendations related to genetic and genomic testing in young women with breast cancer, as well as to offer actionable recommendations to improve value and service for the ACBCYW.

Ms. Dedmon reviewed the previous recommendations of the workgroup, which were:

- Support and provide educational materials for understanding terminology related to genetics and genomics.
- Various types of testing.
- Synthesize reliable information about genetics and genomics in a central educational platform.

- Explore education regarding pathologic risk factors.
- CDC to join the Consistent Testing Terminology Working Group to stay informed and participate in discussions to develop specific language around genetics and genomics.

Sue Friedman interjected to note that the Consistent Testing Terminology Working Group sunsetted and with it the recommendation to CDC.

Ms. Dedmon discussed the proposed recommendation. In terms of provider-level barriers, the problem is that genetic testing for inherited mutations is still largely underused in breast cancer. The objective is to enhance awareness of resources, accessibility, and use of genetic counseling and testing services through CDC's National Comprehensive Cancer Control Program (NCCCP). One action CDC can take is to promote national programs and resources focused on facilitating genetic counseling and testing to the NCCCP. She discussed details about that recommendation, such as looking for opportunities for a resource directory, partnerships with national organizations, funding and grants, guideline dissemination, and evaluation and feedback.

Another objective related to the provider-level barrier is to expand access to information about genetic testing for breast cancer by leveraging new point-of-care partners. One action CDC can take is engaging new point-of-care partners such as front-line care pharmacies and pharmacists and minute clinics. She discussed details of this recommendation, such as awareness campaigns with pharmacies and pharmacists and providing patient education materials to minute clinics.

Ms. Dedmon then discussed the problem of breaking down patient awareness and consideration barriers to genetic testing for inherited mutations in breast cancer. The objective is to raise awareness about breast cancer risk in young women and promote genetic testing. She noted one action CDC can take is to continue the *Bring Your Brave* campaign.

Transitioning to the discussion of disparities, Ms. Verinda Hobbs expressed that despite the urgent need to address disparities in genetic testing for breast cancer, there is a lack of comprehensive assessments, targeted outreach, awareness of National Comprehensive Cancer Network guidelines, and mechanisms to measure barriers, which hinders equitable care. Actions that CDC can take include more outreach work with American Indian and Alaska Native populations to improve access to genetic testing and support for those communities.

There was discussion about how tribal legislation and ethnic priorities can be barriers to genetic testing and research, leading to barriers to biomarker-informed treatment.

Ms. Hobbs refocused the conversation on disparities by discussing details of proposed outreach, such as:

- Campaign enhancement and remarketing:
 - Expand the *Bring Your Brave* campaign with a specific focus on genetic testing.
 - Highlight the importance of understanding one's genetic risk in people without family history or mutation.
- Story sharing:
 - Continue to collect and share stories from young women who have undergone genetic testing, focusing on their motivations, experiences, and outcomes.
- Targeted messaging:
 - Develop targeted messaging for American Indian and Alaska Native populations, their families, and health care providers, emphasizing the role of genetic testing in early detection and prevention.
- Community engagement:
 - Work directly with tribal health organizations and community leaders to understand specific needs and barriers related to genetic testing.
- Culturally relevant materials:
 - Develop and distribute culturally sensitive educational materials about genetic testing and its benefits.

- Local workshops:
 - Organize workshops and informational sessions in collaboration with local health providers to educate communities about genetic testing.
- Support services:
 - Provide resources and support for navigating the testing process, including transportation and financial assistance if needed.
- Partnerships:
 - Build partnerships with American Indian and Alaska Native health organizations to facilitate outreach and improve testing uptake.

Ms. Hobbs noted that an action CDC can take is creating campaigns to increase awareness and access to genetic testing for gender minorities and gender-diverse individuals at high risk for breast cancer. She discussed the details of this action, such as awareness campaigns, resource dissemination, health care provider training, inclusive education materials, barriers measurement, and support networks.

Ms. Dedmon spoke again, highlighting critical areas of exploration that the workgroup did not get a chance to discuss, such as access to care, risk without family history or mutation, and understanding genetics and genomics (biomarker testing). She cautioned that it's important to be considerate in their messaging because if family history and mutations are always discussed, it will lead people to think that if they don't have a family history, they don't have a mutation or they don't need to be concerned. She referred to a QR code for EasyRetro (on the screen) that allowed committee members to add input or items for consideration. Ms. Dedmon concluded by stating the workgroup had nothing to vote on today, as they wanted to capture information in the critical areas mentioned so they could create a comprehensive list before submitting anything formal.

Mental Health Workgroup

Ms. Maimah Karmo began by giving an overview of her involvement with the committee, as well as noting the current workgroup members. She spoke about issues women are facing when going through breast cancer and the gaps the workgroup identified. In terms of overlooked needs, Ms. Karmo stated:

- Perception of being a “warrior” can be shaming and isolating.
- Shame around loss of life as we know it: body image, stolen dreams, fertility, letting others down.
- Fear of recurrence can be debilitating and long-term.
- Having to “suffer through” and be thankful.
- Anger around cancer and issues like stolen fertility and future as it was planned.
- For advocates, it becomes their entire life. They face extreme pressure to go nonstop, which is not healthy. People should not be shamed or feel isolated if they just want to live.

In terms of overlooked needs in children, Ms. Karmo stated:

- Fear of parents' re-diagnosis, particularly a single parent.
- Anxiety shapes the child's life.
- All they hear about is cancer and death.
- Feel guilty and don't want to make it about them, or be a further burden by sharing their feelings.
- They feel their feelings are less significant than what their parents are going through.
- There is an opportunity to provide therapeutic support and a space to be authentic and vulnerable and coach both (together or separately).
- Need to provide age-appropriate support to children and family, caregivers, and peers.

In terms of overlooked needs in the BIPOC populations, Ms. Karmo stated:

- Stress of reliving trauma around health care, racism, and demands on this community, with so much focus on reliving trauma around being Black or Brown, in addition to the everyday pressures of living and how the world sees them.

- Navigating stigma in lesbian, gay, bisexual, transgender, queer (or those questioning their gender identity or sexual orientation), intersex, and asexual (or their allies) (LGBTQAI) populations.

Ms. Karmo brought up the idea of what “whole person healing” looks like and how there needs to be more focus on identity, grief, abandonment, and relationships. With breast cancer, there is added trauma and long-term stressors, especially in MBC, TNBC, and BIPOC populations. She discussed handling the mental weight of cancer and how it disrupts life. There is also early-age menopause and the lack of choice around certain issues that need to be considered.

Ms. Karmo discussed recommendations, such as:

- Conduct a gap analysis cross-matrixed with identified needs and services (member, community and open source).
- Continuing to identify needs and gaps in available resources.
- Identify mental health experts who can support this work.
- Potential solutions:
 - Educational content
 - Listening sessions or tour
 - Campaign on candid conversations and vulnerability (op-eds, media, video, social media)
 - Insurance
 - Policy

Ms. Karmo concluded by saying that the workgroup would love to get input and thoughts from the committee members and if someone is open to joining the workgroup, they are welcome to do so.

Questions and Answers

Dr. Checka referred to the *Bring Your Brave* campaign presentation from the morning session that had a young woman smiling with a quote about it being challenging to present a happy face when you may not be happy; that you bear the burden for managing others’ feelings around you. It also reminded her of a direct-to-consumer TV ad for a medication for a refractory type of depression with a woman holding up a smiling face on a stick. Dr. Checka pondered whether there might be a third group that could be added to the two groups (adults and children) mentioned when the workgroup highlighted the needs of patients and children, which is partners and caregivers. She also noted some patients have to face this completely alone. This is another reproductive health issue for someone who is not partnered and already having to think about family planning.

Ms. Karmo agreed, stating the workgroup welcomes feedback. The presentation mentioned the LGBTQAI population; however, the workgroup was not able to develop it given the time constraints. She would love for people to bring themselves and their vulnerability to the table.

There was a comment about how important it is to include the advocate in the mental health conversation, which this workgroup did. A discussion followed on how advocates sometimes have to step back from their role because they are tired, and how important it is to stop people from doing that by helping them understand it’s normal to feel that way or by giving them strategies to stick with it.

Dr. Checka spoke about decisional regret and asked Dr. Howard, “From the plastic surgery perspective, do you all encounter undertreated mental health needs?” Dr. Howard replied that yes, they address it head-on and as part of patient care by giving recommendations to each patient, so they have some kind of support in addition to the people in their household. He noted it’s a tough topic because it’s not one-size-fits-all, but there are several options for both treatment and recovery. It’s not a trauma situation so there is some time to consider the options. It comes down to expectation management and finding out where the patient is coming from to get the individual the best treatment plan.

A comment was made highlighting that the needs of previvors were largely overlooked in the discussion and emphasized the importance of ensuring this group receives appropriate resources as well.

Comments were raised about the lack of sufficient data and literature on patient-reported outcomes, noting the difficulty in measuring them and the potential disconnect between clinicians' priorities and what patients consider important.

Dr. Checka mentioned a validated questionnaire developed at Memorial Sloan Kettering called The Breast-Q, which is a patient-reported outcome measure designed to evaluate outcomes among women undergoing different types of breast surgery.

Ms. Karmo recounted the story of a patient who was so overwhelmed she tried to take her own life, and that's not often talked about.

Dr. Checka opened the question and answer session to committee members on the phone. There was a comment that some of these issues also tie into the lack of integration in the health care system and how a mechanism like care planning can be used to check on the patient's priorities and address them as they evolve, thinking about primary care potentially being at the center of this.

A comment was made about the need to find mental health care providers who accept insurance.

Open Discussion

Dr. Checka recapped the committee's last virtual meeting, the committee's focus and desire to help people with early detection tools, and the reality that there's a lack of a common language even before the detection stage: not everyone knows what breast health is. She noted that the committee will formulate a letter for the Secretary of the Department of Health and Human Services.

After the last meeting, it was mentioned that the committee may have an opportunity to write an editorial that represents the group, and a document has been started. Dr. Checka noted that she recently attended a session by the Association of Surgical Education specifically on how to write an editorial, and she can circulate that video to the committee.

Dr. Checka suggested creating a map for this piece so they know where they're going. They can brainstorm on which academic journal would suit all of their needs, then work backwards to get the desired-length document. She noted this may be a way to get more public eyes on some of the topics mentioned in today's discussion. It could be an opportunity to have a blurb on the groups represented in the committee with carefully worded calls to action at the conclusion.

This idea was discussed, with the consensus that it was a good goal. A suggestion was made to focus the piece through a CDC perspective, meaning to adhere to enhancing public health and doing the greatest good for the greatest number of people.

The discussion turned to which publications may be best to pitch to. Some publications mentioned include the *Journal of the American Medical Association (JAMA)*, the *New England Journal of Medicine*, the *Journal of Clinical Oncology*, *Cosmo*, *Vogue*, and the *New York Times*. It was noted that this piece may be more credible if it was published in a journal, but mainstream media will get more attention. Dr. Checka said she had in mind an op-ed piece in a publication like the *New York Times*.

Dr. Checka reiterated that a document had already been created, which she titled Updates from the Field. Some topics it covers are: what's normal; a statement of problem; some background, including prior studies; barriers that may exist; and benefits. She noted there could be an opportunity to highlight the committee's liaisons and member organizations' work, and end the piece with calls to action.

A comment was made that it may be best to assign sections to certain people so committee members work in areas they're stronger in. A second comment was made that the majority of the legwork was done today, and the committee can refer to the record of the meeting for this piece's framework.

There was a comment about how it's competitive to get published in a publication like *Cosmo*, and the committee could use local news organizations to get attention and target people who wouldn't otherwise have access to this information. There was also a comment that the economics of this should be considered, specifically how to generate the money to pay for it.

A discussion on the framework of this document ensued and it was noted that agreeing on the calls to action at the end could be difficult. It was also noted that these calls to action can be kept general because there will be an opportunity to include action items in the formal document as well.

The question was asked, "Are we able to publish something as representatives of CDC?" Dr. Temeika Fairley responded, "Not as a representative of CDC." She noted that federal advisory committees are freestanding entities according to the law, and it needs to be stated up front that this is not representative of CDC. No CDC staff can author it.

Dr. Fairley noted that CDC needs help with areas left out of today's discussion relating to providers, specifically issues with system-level next steps and point of contact work to gain a greater reach. Regarding genetics and genomics, Dr. Fairley mentioned she would be interested in discussing their work, specifically around certain communities—gender minorities, American Indians, and Alaska Natives—as historically they have not been easy audiences to craft information for.

A discussion around genetics and genomics ensued, with comments made about oncology testing and germline genetic testing, how biomarker testing is part of what the workgroup is looking at, and overtreating patients.

Public Comment

Dr. Checka noted that no written public comments or questions were received. There was a comment from a member of the public in attendance, Allison Anbari of the University of Missouri. She noted that the committee can choose a publication like *JAMA* or the *New England Journal of Medicine* for the op-ed piece, then issue a press release that is essentially a shortened version, with the hope that a publication like *Vogue*, *Cosmo*, or the *New York Times* reaches out for an interview.

Summary and Closing

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

Dr. Checka thanked all of the members. She challenged everyone to go back to their respective centers, jobs, and institutions and bring back fresh energy with the message that the committee has heard from them, and to share what the committee discussed and learned today with their respective communities.

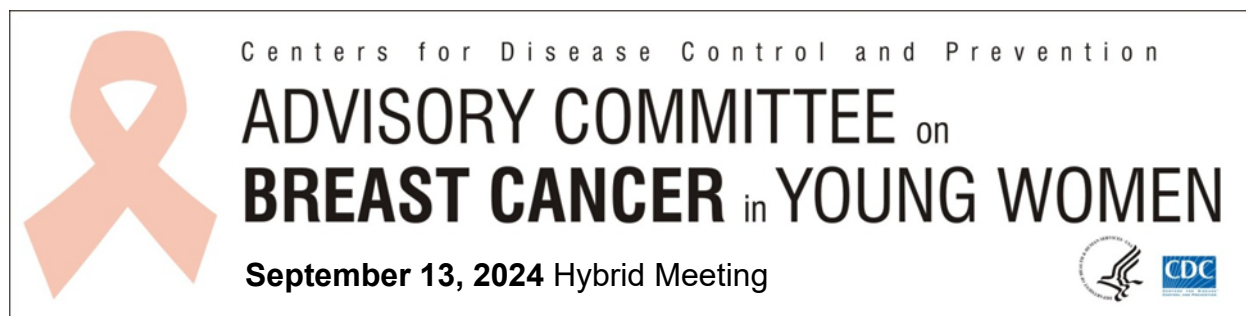
With no further verbal comments or questions, the meeting adjourned at 3:16 p.m. Eastern Daylight Time.

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



Agenda

MEETING OBJECTIVES

To advise the Secretary of the Department of Health and Human Services (HHS) and the Director of the Centers for Disease Control and Prevention (CDC) 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).

*All times are in Eastern Time

Friday, September 13, 2024

8:30 A.M. – 9:15 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

9:15 A.M. – 10:00 A.M.

CDC Updates

Temeika L. Fairley, PhD
Senior Health Scientist
CDC, Division of Cancer Prevention and Control

Ally Moehring
Health Communication Specialist
CDC, Division of Cancer Prevention and Control

10:00 A.M. – 10:15 A.M.

Committee Chair Updates

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

10:15 A.M. – 10:30 A.M.

Break

10:30 A.M. – 11:45 A.M.

Updates from the Field

Ricki Fairley, MBA
Chief Executive Officer
TOUCH, The Black Breast Cancer Alliance

Verinda Hobbs
Partnership Strategy Manager
FORCE: Facing Our Risk of Cancer Empowered

Samantha Lynn Heller, PhD, MD, FSBI
Associate Professor of Radiology Perlmutter Cancer
Center
New York University School of Medicine

11:45 A.M. – 12:45 P.M.

Lunch

12:45 P.M. – 2:00 P.M.

ACBCYW Workgroup Reports and Open Discussion

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

Provider and Healthcare Systems Workgroup

Reproductive Health Workgroup

Genetics and Genomics Workgroup

Mental Health Workgroup

2:00 P.M. – 2:15 P.M.

Break

2:15 P.M. – 3:15 P.M.

ACBCYW Open Discussion

3:15 P.M. – 3:30 P.M.

Public Comment

3:30 P.M. – 4:00 P.M.

Summary and Closing

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

Appendix B



Chair

Cristina M. Checka, MD
Associate Professor
Breast Surgical Oncology
The University of Texas MD Anderson Cancer Center
League City, TX
Email: cmchecka@mdanderson.org
Term: May 17, 2021 to November 30, 2024

Executive Secretary

Kimberly E. Smith, MBA, MHA
Designated Federal Official
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Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
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Term: May 13, 2021 to November 30, 2024

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Arin Ahlum Hanson, MPH, CHES
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Samantha Lynn Heller, PhD, MD, FSBI
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Term: May 14, 2021 to November 30, 2024

Leigh Hurst
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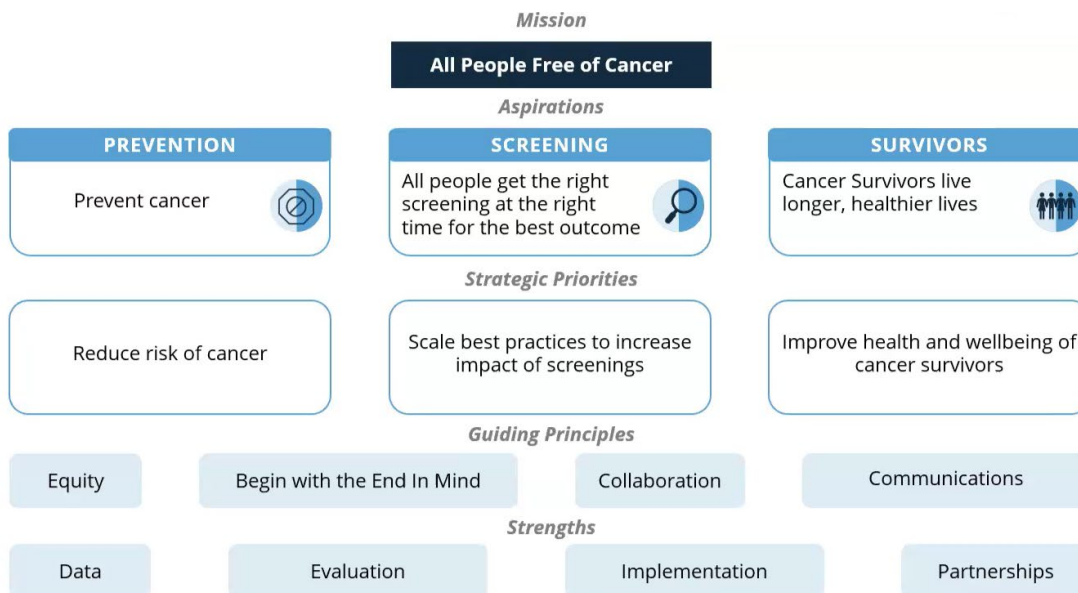
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Appendix C

Strategic Priority Framework



Mission: All people free of cancer.

Aspirations:

- Prevention: Prevent cancer.
- Screening: All people get the right screening at the right time for the best outcome.
- Survivors: Cancer survivors live longer, healthier lives.

Strategic priorities:

- Reduce risk of cancer.
- Scale best practices to increase impact of screenings.
- Improve cancer survivors' health and well-being.

Guiding principles:

- Equity
- Begin with the end in mind
- Collaboration
- Communication

Strengths:

- Data
- Evaluation
- Implementation
- Partnerships