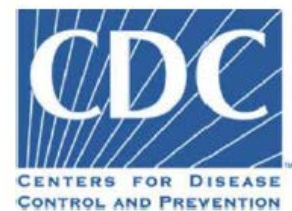


**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION**

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



**Meeting of the
Advisory Committee on Breast Cancer in Young Women
August 19–20, 2019**

Draft Record of the Proceedings

TABLE OF CONTENTS

OPENING: ACBCYW ROLL CALL.....	1
DAY 1: WELCOME AND DCPC OVERVIEW	2
INTRODUCTION AND REMARKS.....	6
OVERVIEW AND HISTORY: BREAST CANCER IN YOUNG WOMEN 10 YEARS LATER.....	8
UPDATES FROM THE FIELD	14
UPDATES FROM CDC	15
DIRECT-TO-CONSUMER TESTING AND EARLY-ONSET BREAST CANCER	19
ACBCYW OPEN DISCUSSION	24
PUBLIC COMMENT.....	26
SUMMARY AND NEXT STEPS	26
DAY 2: WELCOME AND ROLL CALL.....	27
REVIEW AND HIGHLIGHTS.....	27
UPDATES FROM THE FIELD	27
ABCYW OPEN DISCUSSION	27
PUBLIC COMMENT.....	41
SUMMARY AND CLOSING	41
ATTACHMENT 1: PUBLISHED AGENDA	i
ATTACHMENT 2: ROSTER OF THE ACBCYW MEMBERSHIP	iv

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

ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN

August 19–20, 2019

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 meeting of the Advisory Committee on Breast Cancer in Young Women (ACBCYW) on August 19–20, 2019.

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 via teleconference or webinar was published in the *Federal Register* in accordance with Federal Advisory Committee Act regulations. All sessions of the meeting were open to the public.

MONDAY, AUGUST 19, 2019

DAY 1: OPENING AND ACBCYW ROLL CALL

Temeika Fairley, PhD

Designated Federal Officer, DCPC, CDC

Dr. Fairley conducted roll call and confirmed that the 13 voting members and *ex-officio* members (or their proxies) in attendance constituted a quorum for ACBCYW to conduct its business on Monday, August 19, 2019. She called the proceedings to order at 8:35 a.m. EST and welcomed the participants to the Advisory Committee on Breast Cancer in Young Women (ACBCYW) Meeting. None of the voting members publicly declared conflicts of interest for any of the items on the published agenda (*Attachment 1: Published Meeting Agenda*).

WELCOME AND DCPC OVERVIEW

Lisa Richardson, MD
 Director, DCPC, CDC

Dr. Richardson provided the committee with an overview of the DCPC. DCPC is located within the National Center for Chronic Disease Prevention and Health Promotion at CDC and is one of the eight divisions in the Center. The Center’s new Director, Karan Hacker, MD, MPH, was being sworn into her new role today.

DCPC is in the middle of a strategic reprioritization. The new emphasis is on prevention. Given the availability of resources, personnel, creativity, and energy, three areas were identified as places where the division is uniquely positioned to make the most impact and to drive outcomes. Those are data, translation and evaluation, and partnerships.

The slide below illustrates the components of the strategic plan. This will be a living document, so that as time goes by, the Division can utilize its agility to easily modify its processes. The Division plans to post the plan to its website by the end of the fall.

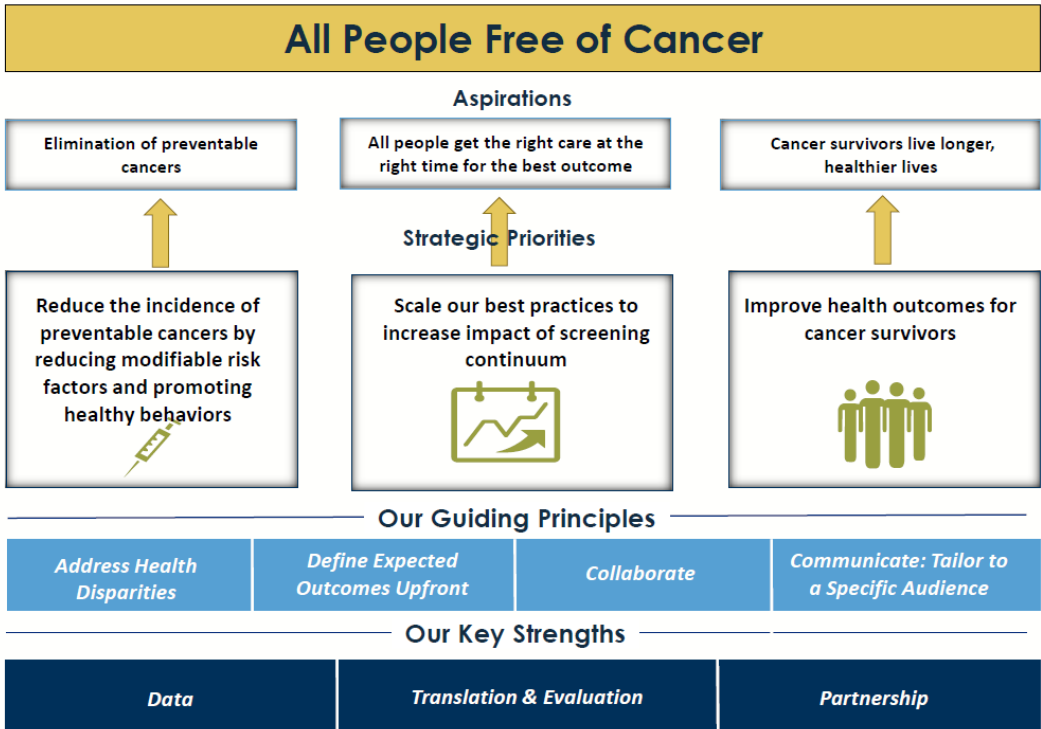


Figure 1. DCPC's New Strategic Plan

Congress has appropriated \$350 million to DCPC. The largest program is the Breast and Cervical Screening Program, which received \$197 million of those funds. Other program appropriations were as follows:

- Cancer Registries, \$51.4 million
- Colorectal Cancer, \$43.2 million
- Comprehensive Cancer, \$19.6 million
- Prostate Cancer, \$13.2 million
- Ovarian Cancer, \$10 million
- Johanna's Law, \$7.5 million
- Breast Cancer in Young Women, \$5 million
- Skin Cancer, \$3 million
- Cancer Survivorship, \$475,000

DCPC is comprised of four programs: National Breast and Cervical Cancer Early Detection Program (NBCCEDP); National Comprehensive Cancer Control Program (NCCCCP); National Program of Cancer Registries (NPCR); and Colorectal Cancer Control Program (CRCCP). Dr. Richardson outlined the functions of each.

National Breast and Cervical Cancer Early Detection Program (NBCCEDP): DCPC was birthed out of this 30-year old program. It is a state-level program, which has a network of screening providers funded by CDC, serving low-income, uninsured, and underserved women. From 2013 to 2017, more than 1.3 million women have been screened as a result of the program, with 13,062 diagnosed with breast cancer, 581 diagnosed with cervical cancer, and 6,711 with high-grade precancerous lesions. These numbers are a slightly lower than those seen in the past due to Medicaid expansion and an increase in women having medical insurance. The work is accomplished with the help of 70 funded grantees who utilized system-level interventions. It serves more than 300,000 women per year.

National Comprehensive Cancer Control Program (NCCCCP): This also a state-program. Its priorities are to:

- Emphasize primary prevention of cancer;
- Support early detection and treatment activities;
- Address the public health needs of cancer survivors;
- Implement PSE changes to guide sustainable cancer control;
- Promote health equity as is relates to cancer control; and,
- Demonstrate outcome through evaluation.

Partnerships, both federal and local, are paramount to the program's work. Most of the partners are unfunded and work along with CDC because they are motivated to find solutions and ensure that people are free of cancer at all stages of the continuum. The program is willing to work with anyone who will come to the table.

National Program of Cancer Registries (NPCR): This program is centered around data and works in partnership with the Surveillance, Epidemiology, and End Results (SEER) Program to estimate cancer statistics for the United States. Incidence and demographic data for all new cancer cases for 100% of the U.S. population, as well as Puerto Rico, are encompassed in this registry. There are 1.7 million new cancer cases each year. The registry contains 200+ data items for each of the cases related to cancer site and histology; patient demographics; stage at diagnosis; and first course of treatment. With the help of this data, roughly 98% of cases are reached before the point of death. It is the who, what, why, where, and when of cancer.

The U.S. Cancer Statistics: Data Visualizations Tool, (www.cdc.gov/cancer/dataviz/). This very intuitive database provides users with access to information on the major cancer types. Currently, data comes from various sources into the state registry and is then distributed to the CDC. In the future, DCPC will seek a methodology to have direct reporting from health records to cloud analytics tools that will structure the data and send it back to the individuals who originally reported the data. Laboratories have shown the most interest in this ability. When a person has multiple providers for their cancer treatment, the laboratories have to send test results to each of the providers. This mechanism will streamline their processes.

Colorectal Cancer Control Program (CRCCP): This program is funded at roughly \$22 million and focuses on creating a system-level integration into primary care systems to enhance its effectiveness in cancer prevention. The tenets of the model include the following elements:

- Integrated public health and primary care
- Focus on defined, high-need populations
- Establish partnerships to support implementation
- Use data for program improvement and performance management
- Implement sustainable health system changes
- Use evidence-based strategies to maximize limited public health dollars
- Encourage innovation in adaptation of EBIs

The reach of the CRCCP grantees is substantial. There are 240 health systems, 761 clinics, and 6,039 providers resulting in 1,240,336 patients aged 50 to 75 being touched. Of the clinics, 70% are Federally Qualified Health Centers (FQHCs), 27% serve a high percentage of uninsured patients (>20%), and 50% use FOBT/FIT tests as the primary colorectal cancer screening test type. Among clinics that enrolled in the first year of CRCCP, colorectal cancer (CRC) screening rates rose an average of 10.3 percentage points (an additional 55,964 screenings) since baseline. This is proof that the new model works. The screening rates have been shown to increase with each additional evidence-based intervention (EBI) implemented.

DCPC devises new ways to help funded grantees work with health systems and health insurers. The StEM Project was created to assist in this effort. This is a collaboration between the National Association of Chronic Disease Directors (NACDD), CDC, and Leavitt Partners. The goal is to increase colorectal cancer screening rates in six states: Alaska, Georgia, Louisiana, Mississippi, Oklahoma, and West Virginia. The project serves as a bridge between the funded grantees and high-level leaders in health institutions and health insurers.

The Cancer Genomics Program aids in translating evidence for implementation in public health programs that benefit people, families and communities. The program has the following priorities:

- New opportunities for cancer prevention
- Cancer screening for high-risk groups
- Improving cancer care
- Understanding cancer risk
- Increasing access, decreasing disparities

DCPC also employs a number of initiatives and campaigns that assist in bringing awareness and increasing screen rates such as Screen for Life, Prostate Cancer Awareness, Bring Your Brave, and Know BRCA.

The Division's history of improving survivor health and quality of life spans back to 2004. It plays several major roles in cancer survivorship. DCPC is the disseminator of cancer survivorship research and health promotion messages. It has a collection of high-quality data on cancer survivorship on national population-based surveys, like the Behavioral Risk Factor Surveillance System (BRFSS), the National Health Interview Survey (NHIS), and the Medical Expenditure Panel Survey (MEPS). It helps to leverage cancer registries, like NPCR/ SEER, to identify and address the unique needs of cancer survivors. Lastly, the Division provides technical assistance and programmatic support to the National Comprehensive Cancer Control Program (NCCCP) and other grantees to address the needs of survivors in their communities.

Numerous approaches are utilized to increase awareness and support for young women who have been diagnosed with breast cancer. The Cancer Cooperative Agreement helps to create a community through the organizations that serve the target population, like Dana-Farber Cancer Institute, Sharsheret, and Johns Hopkins Bloomberg School of Public Health. In addition, the agreement helps expand the availability of health information and support services for young breast cancer survivors and their families.

DCPC also utilizes internal partners to spread its message. The National HPV Vaccination Roundtable is a collaboration with the American Cancer Society, CDC (DCPC and the National Center for Immunization and Respiratory Diseases), and other partners, whose aims are to expand the reach of current CDC immunization and

comprehensive cancer control programs, as well as establish HPV Vaccination State Affinity Groups, like the Centers for Medicare & Medicaid Services (CMS), CDC, and the Health Resources and Services Administration (HRSA). The goal is to promote HPV as a cancer vaccine.

Cancer Prevention Across the Lifespan is an effort to foster innovative public health approaches to cancer prevention through every stage of life. CDC recently published a paper which examines what is important, what is missing, what can be done now and ways to complete the work, as well how the answers to those questions differ across the lifespan. Another progress report was released for skin cancer prevention. This report highlights all the new data that has surfaced in the current year.

The Division also has tools that utilize virtual humans to improve patient-provider communication and tackle the barriers patients face. Below is a description of some of the programs being utilized.



Figure 2. Health and Literacy Professional Development, Virtual Human Tools

After the presentation, Dr. Fairley asked the ACBCYW Members to introduce themselves and their organization/agency (*Attachment 2: Participants' Directory*).

INTRODUCTION AND REMARKS

Elana Silber, MBA
Sharsheret
ACBCYW Committee Chair

Ms. Silber presented her organization, Sharsheret, where she serves as the Executive Director. She has been working in the breast cancer field for 17 years.

Sharsheret is 18 years old and was started in 2001 by Rochelle Shoretz, a Jewish woman. She noticed that there was a lack of information for young Jewish women with cancer related to their day-to-day demands like balancing young kids, being married, having a career, and their breast cancer diagnosis. She and a friend, Lauryn Weiser, who was also dealing with the same challenges as a young Jewish woman, decided to start an organization to help women like themselves. Sharsheret means “chain.” Now, thousands of Jewish women and families are a part of the Sharsheret community. There are over 30 staff members and four offices. Four years ago, Ms. Shoretz passed away from complications due to breast cancer.

Sharsheret is a national non-profit organization that improves the lives of young Jewish women and families living with or at increased genetic risk for breast cancer. It achieves this goal through personalized support and educational outreach. For Jewish women, 1 in 40 of Ashkenazi descent carries a BRCA gene mutation, compared to 1 in 500 in the general population. This means that Jewish families have a 10-time greater risk for hereditary breast, ovarian, and related cancers; therefore, it is paramount to educate the community about their risks. There are other mutations and some yet to be identified that plague this community as well, so Sharsheret shares statistics widely to bring attention to the data and increases opportunities to educate.

When Sharsheret started in 2001, emerging studies showed a need for breast cancer organizations and health care professionals to design educational materials and resources that were sensitive to diverse cultural and ethnic backgrounds. Religion and culture play significant roles in breast cancer. In the Jewish community, people turn to religion, support, God, and community to find strength and encouragement. Having an organization that understands the culture gives a sense of community within a community.

There are cultural challenges when coming to the Jewish communities. In ultra-orthodox and secular communities, women use ritual baths for healing after chemotherapy. Women in some cultures may cover their hair due to hair loss, but in the orthodox community that is a symbol of marriage. Even high holidays, the new year, which is for most cultures a time of jubilation, in the Jewish religion services contain prayers that focus on who shall live and who shall die, which can be daunting when diagnosed with a serious illness. Sharsheret’s services go across the religious spectrum and deal with struggles personally as well as the questions women and their families face in the Jewish community.

Programs for the organization fall into two buckets: support and education. These are for women and men, since the BRCA mutation is also found in men and can be passed on to the next generation. The gene also increases a man’s risk for other cancers, like prostate.

The Peer Support Network services 14,000 women. A database matches the women to others with similar diagnosis, background, and concerns. This is a very tailored process.

The network empowers the women to make informed decisions about their health. Everything is confidential, anonymous, and free.

Another service offered is patient navigation. This is done by phone, email, and live chat. There are eight social workers and a genetic counselor on staff. Calls are taken 24 hours, a day 7 days a week. The live chat allows women to access someone any time of the day. All social workers are well versed in day-to-day challenges of a Jewish woman as well as the cultural background. Some non-Jewish women reach out as well (15 to 20 percent) because they like the personalized services provided.

The organization also provides education regarding the unique cultural issues and genetic heritage of Jewish women. They have partners with major medical practices to train an array of health care professionals. They also disseminate information to the community through a resource series; more than 100,000 booklets are distributed a year. In addition, Sharsheret hosts webinars three to four times a year on topics requested by the women served. Their next webinar will occur on September 17, 2019 and will cover treatment and insurance.

The organization's signature community event is the Sharsheret Pink Shabbat. This event brings the Shabbat experience to campuses and communities and provides an opportunity to share information regarding breast cancer risks, signs, and symptoms.

Ms. Silber ended her presentation by sharing a YouTube video called Rachel's Story. The video gives the perspective of a client's experience with Sharsheret.
<https://www.youtube.com/watch?v=itNCawQkpl>.

OVERVIEW AND HISTORY: BREAST CANCER IN YOUNG WOMEN 10 YEARS LATER

Temeika Fairley, PhD

Designated Federal Officer, DCPC, CDC

Dr. Fairley provided the board with a review of progress made in the past 10 years for young women with breast cancer. She began by giving some background information regarding breast cancer. Breast cancer is the most commonly diagnosed cancer among women. Approximately 11% of invasive breast cancer cases occur among women younger than age 45. These women often face difficult medical, psychosocial, financial, and health issues related to their diagnosis and treatment. Nearly 30% of women diagnosed with early breast cancer develop metastatic breast cancer (mBC) with an expected median survival rate between two to four years.

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

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

The CDC's grant called Multiple Approaches to Increase Awareness and Support among Young Women Diagnosed with Breast Cancer currently funds seven grantees: Sharsheret, Young Survival Coalition, Dana-Farber Cancer Institute, Johns Hopkins University, LSU Health Science Center, Living Beyond Breast Cancer, and FORCE. This is a five-year cooperative agreement (2014 to 2019), with a second agreement forthcoming.

Dr. Fairley presented some of the grantees' work. Johns Hopkins University is working to enhance delivery of care and wellness from the first visit through the continuum of care. They offer one-on-one patient navigation, which serves 425 young women per year. Also available are various psycho-educational peer support groups for young women with early stage and metastatic breast cancer. The University offers an online nutrition course with an accompanying recipe booklet. There is access to fitness and wellness through gym partnerships and online programming, which aid in reducing barriers to exercise.

In the 2018 to 2019 year, [Johns Hopkins Medical Young Women's Breast Cancer Program](#) distributed information binders to 200 young women. They have held three webinars that had a global reach (600 real-time participants; 1,200 archived webinar views). In addition, they have 70 website videos with distinct topics in their library. These videos are viewed roughly 600 times per month. Lastly, mobile app tools are available to patients for scheduling, education, navigation, and treatment.

[Sharsheret](#) offers the Thriving Again Survivorship Program. During the 2018 to 2019 grant year, the program:

- Disseminated 154 updated Thriving Again wellness kits to young breast cancer survivors (YBCS).
- Presented BRCA genetics webinar for 400+ participants, featuring updated information on new recommendations in genetic testing.
- Implemented online, patient navigation resources for YBCS and caregivers.

- Conducted 2 peer support and story sharing training webinars for 112 YBCS.
- Established partner network of 90 agencies providing YBCS support in local communities.

FORCE has the [XRAYS Program](#), which stands for eXamining the Relevance of Articles for Young Survivors. This program helps young breast cancer survivors and women at high risk to better understand breast cancer research and news that is relevant to them. XRAYS allows users to submit articles for review and subscribe to an XRAYS quarterly digest. In the 2018 to 2019 project year, 38 XRAYS article reviews were published, as well as 10 blog posts created about the XRAYS program. The program reached 140,000 readers.

LSU Health Science Center has created the [Gulf States Young Breast Cancer Survivor Network](#) (GSYBCSN). This is an online health resource for young breast cancer survivors living in Louisiana, Alabama, and Mississippi. It started as digital platforms: SurviveDAT in Louisiana; SurviveAL in Alabama; and SurviveMISS in Mississippi. The purpose of the program is to provide services and support for young breast cancer survivors including those with metastatic cancer, as well as their caregivers and families in the gulf states region. During the 2018 to 2019 grant year, they developed a video-based psycho-social support series with a board-certified oncology counselor, which will be rolled out over the next 5 months. They also disseminated educational information to 852 physicians across the three states to update them on concerns important to young breast cancer survivors. In addition, they developed and leveraged new partnerships by collaborating with Komen affiliates on a metastatic Breast Cancer Conferences in Louisiana and Mississippi; participated in Alabama's annual Women's Cancer Survivor's Workshop; and attended the Young Survival Coalition's Annual Summit for young breast cancer survivors, as well as FORCE's annual conference.

The [Young Survival Coalition](#) manages a large program for young women and survivors that is focused on peer support. It also hosts a national and regional summit. There were 507 attendees at the last summit, and 98% of the attendees are cancer survivors. This is a very impactful experience. Eighty-one percent of the attendees agreed that they learned something new due to the subject matter experts and researchers and providers, information regarding new tests, medicines, and treatments. A strong survivorship component built into the summit as well.

Dana Farber offers the [Young and Strong Survivorship Program](#). In the fall of 2018, it hosted the Forum for Young Women with Breast Cancer, which had 95 attendees. Their YBCS Navigated to Survivorship Program had 105 visits. They also hosted three phone support groups with young breast cancer survivors and two sexual health workshops for couples and young breast cancer survivors. The program also produces webcasts on topics relevant to young breast cancer survivors.

Living Beyond Breast Cancer implemented the [Survivorship Series for Young Women](#) to be delivered by trained professionals within cancer centers that serve underserved

young breast cancer survivors. They also have a collaboration with medical centers nationwide building on its extensive engagement with the medical community. The program has trained 15 nurse navigators; seven of those navigators had engagements with 126 young breast cancer survivors. It is anticipated there will be up to 200 additional young breast cancer survivors reached by the end of 2019. Their program is being evaluated by CDC for utility and scalability.

With regards to applied research, the BCYW Program has completed a number of activities, such as:

- Walking Together: Making a Path toward Healing: Examined early onset breast cancer in the Native American community.
- Literature Review/SME Panel: Breast Cancer in Young Women: Reviewing the Evidence and Setting the Course.
- Estimating Infertility Among Breast Cancer Survivors.
- Health Insurance Coverage of Genetics Services.
- Economic Burden of Breast Cancer in Young Women Aged 15-44 Years in the United States, 2000-2010.
- Economic Impact of Late Stage Breast Cancer Diagnosis and Benefits of Reducing Alcohol Consumption Among Women Aged 18-44 Years at High Risk for Breast Cancer.
- Sisters Study and Two Sisters Study: national survey of young breast cancer survivors and their sisters.

The program also examines the economic impact caused by breast cancer in this population. One of their studies assesses the lifetime economic burden in younger, midlife, and older women with metastatic breast cancer. This is an ongoing study which estimates the economic factors related to metastatic breast cancer as it relates to loss of productivity, direct costs, years potential life lost, and cost of care per population. A literature review was published in Breast Cancer Research and Treatment in January 2019. It is anticipated that additional findings will be available in early 2020.

Another study is the Economic Wellbeing of Young Women with Breast Cancer. The purpose of the study is to evaluate the insurance, employment, and financial experiences of young breast cancer survivors and assess factors associated with financial decline. The targeted population will include female breast cancer survivors, under the age of 40, recruited through California, Florida, Georgia, and North Carolina population cancer registries. There will be six questions related to insurance, 11 on financial burden, 13 pertaining to employment, and other topics such as demographic information, access to care, and cancer history will be included as well.

There are multiple publications in draft regarding the findings, but overall the study concluded that young female breast cancer patients experience substantial financial burden, even with insurance. In addition, this population have to make difficult

employment decision, often based on health insurance maintenance. Lastly, almost half experience a decline in financial wellbeing due to breast cancer treatment. It is anticipated that additional findings will be available in early 2020.

The Early Act Legislation also includes an education piece. Not only is there a component for young women with breast cancer and those who may be at risk, but there is also an initiative to provide education to health providers. There have been challenges in completing this task. There is an assumption that providers know exactly the what, how, and when for breast cancer, which may not be accurate. A couple of projects have been designed to address this issue.

The Bring Your Brave Project is funded by CDC's Cooperative Agreement OT18-1802. This is a structured, story-based, educational training program for health care providers. It is a collaborative work with the American College of Obstetricians and Gynecologists (ACOG). There is a continuing medical education (CME) component. The CME module is a total of seven credits. The goal is to develop innovative, evidence-based provider education materials on early onset breast cancer with input from stakeholders. The project is expected to be available in January 2020.

There has been some campaign work occurring as well. Know: BRCA is an interactive online tool that estimates a woman's chance of having a BRCA gene mutation based on personal and family history of breast and ovarian cancer. It also provides health care providers with the patient's information, with permission, as well as talking points. It was created in 2009 and retooled in 2010. From 2014 to 2018, more than 122,000 users visited the site, with 4,200 users per month visiting the site in 2017. There were more than 77,000 views of the Know: BRCA's Learn the Facts pages, and 4,072 women have completed the Know: BRCA assessment and learned their risk for a BRCA gene mutation. Roughly 581 providers have downloaded a starter kit to explore using Know: BRCA in their practice with more than 15 starter kits downloaded each month on average. The program has been sunsetted and the next iteration is being created.

Out of Know: BRCA, the Bring Your Brave Campaign was created. It was also developed as a result of some of the recommendations received from the ACBCYW in 2014 and 2015. It is a multimedia storytelling campaign targeting young women and health care providers, with an emphasis on young women at higher risk for early-onset breast cancer (including HBOC). This is primarily digital utilizing several platforms, like Facebook, Twitter, YouTube, Tumblr, LinkedIn, and Instagram. It is also available on CDC's website with resources for young women and health care providers. A Medscape-Continuing Medical Education (CME) training has also been developed. And lastly, the campaign utilizes paid media.

The campaign objectives are to reach young women and:

- Encourage them to learn their family history.
- Educate on the risk factors for breast cancer before age 45.

- Inspire women to talk to their health care providers if they think they may be at a higher risk for breast cancer.
- Incite women to live a healthy lifestyle and be aware of their own breast health.

The campaign has generated:

- 114 million impressions across social media, blogs, search engines, digital display, and earned media;
- 2.28 million video views;
- 1.4 million social media engagements; and
- 337,000+ visits to CDC's Bring Your Brave website.

It has also received a CDC Award for Excellence in Communication and a Certificate of Excellence: Public Service through the Public Relations Society of America. Most importantly, campaign efforts have encouraged thousands of women to learn their family history of breast cancer and be aware of their own breast health.

In 2017, CDC initiated the health care provider component of the campaign. Formative research data was utilized to create the program using methodologies such as DocStyles survey of doctors regarding HBOC, literature reviews, and Medscape survey of internal user needs. The Bring Your Brave Health Care Provider website was launched. It includes risk assessment tools and screening guidelines; tailored, downloadable fact sheets; and access to a CME training course. The Medscape CME training for health care providers was launched 2017 and provider education training videos were created in 2018. Since the Medscape CME launch in late January 2017, the Bring Your Brave Health Care Provider CME has resulted in 14,849 learners, 7,328 test-takers, 7,174 CME certificates issued, and 10,738.75 CME credits. Positive feedback was given from those who completed the CME training. It was discovered that 85% of the participants were nurses, so more thought is being given on ways to better promote and disseminate trainings to physicians.

More formative research is underway. The Bring Your Brave Campaign is also moving into the direct-to-consumer genetic testing space to bring awareness. Lastly, there are ongoing efforts to increase education to providers so that they are better able to engage with their patients.

Comments from the ACBCYW:

- There are a large number of self-employed or entrepreneurs in this population, and it is a challenge to help those individuals access the care they need because they are not necessarily underserved, but are self-employed. Some of them do not have a primary care physician or are not visiting their OB-GYN very regularly.

- Young adults are a special population and are in and of themselves underserved. Research shows that they have not had the opportunity to build savings or grow and access a 401(k). Many have to move back home due to financial burdens.
- There needs to be a CME on ACOG for survivorship issues. Some breast cancer survivors may not have access to a traditional survivorship clinic. Think of equipping primary care providers and family practice providers with tools to help care for those individuals.
- When framing solutions, determine health systems solution, like CMS, that can improve financial impact across the board, not just for breast cancer, because the impacts are probably similar for any serious diagnosis for young people.
- This is an opportunity to collaborate with national nonprofit partners who are doing this type of data sampling with their population. Bringing all of the data together will tell a broader picture of the true economic impact of these conditions across populations of race, ethnicity, geography, etc.
- The financial impact of fertility treatments needs to be studied. This is a huge concern for this population. Most treatments start at \$10,000 and go up.
- Consider partnering with large health systems to reach more providers for the CME and provider education components.
- Be careful not to give up on ideas too quickly, such as the idea of sunseting the Know: BRCA project. Communities of color may be a little slower in their uptake of these programs. When they are finally directed to these resources, they have been discontinued. The assumption is that everyone is learning at the same rate, which is not necessarily true. Give time for penetration.

UPDATES FROM THE FIELD

Justin Trogdon, PhD

Associate Professor, Health Policy and Management
UNC Gillings School of Global Public Health

Dr Trogdon's work focuses on estimating the economic burden of breast cancer in young women. Today's presentation showcased some of the preliminary results from his latest study, which centers on metastatic breast cancer across the lifespan. He serves as a coprincipal investigator (PI), along with his counterpart Stephanie Wheeler. The project is funded by SIP 17-004.

The team first tried to assess the cost of breast cancer at a population level, but found it difficult to assess metastatic breast cancer costs using that methodology. Therefore, the decision was made to measure the burden directly. He shared the initial results across three aims of the project. The first aim was a broad sense of the economic burden which examined direct costs, such as medical costs and indirect, such as loss of productivity. Studies show that productivity is more important to younger women than in

older women. The second aim looks at the estimates on a per person basis and then scale the results to what is occurring in the U.S. and what might occur in the next 15 years in terms of trends of the burden. The third aim will model some of the treatment pathways as it relates to cost effectiveness. It is anticipated that additional findings will be available in early 2020.

Comment from the ACBCYW:

- It would be interesting to look at the genetic mutation status among this population to determine if they were aware, they had a mutation, if they knew at the time of diagnosis and correlate that with cost effectiveness of genetic testing.

UPDATES FROM CDC

Bring Your Brave Campaign Formative Research

Natasha Buchanan Lunsford, PhD

Behavioral Scientist, DCPC, CDC

Dr. Buchanan Lunsford is a behavioral scientist. She has worked closely with the program on survivorship and the campaign in term of behavioral health research. Her presentation highlighted the formative research used in the Bring Your Brave Campaign. The research helps in understanding the target audiences' knowledge, awareness, beliefs, and behaviors related to a number of topics, as well as provides an opportunity to test messages and materials that have been created for the campaign.

The formative research began in 2015. A total of 12 formative research efforts have been conducted. The work included 54 focus groups, 49 individual or key informant interviews, a gap analysis, and two environmental scans. The work focused on three target audiences:

- Young Women
 - Segmented by age, race/ethnicity, and family history status
- Family Members
- Health Care Providers
 - Physicians (e.g. OB/GYN; PCP)
 - Nurse Practitioners
 - Physicians Assistants

For family members, focus groups were utilized to gather data. The purpose of the focus group was to understand the dynamics of communication among multigenerational female family members affected by breast and ovarian cancer (KAB and material testing) to study the differences in the way information is shared,

willingness to share information or hesitancy, tone of discussion within families, as well as the topics discussed. Twelve family unit focus groups were conducted in Miami, Florida and Dallas, Texas from June to August 2017. They lasted for approximately 90 minutes and were moderated by female moderators, who possessed relevant experience and shared reported participants' race or ethnicity. Each group had one woman who was between the ages of 18 and 44 years old and one to three family members who were female and shared a family history of breast or ovarian cancer. Additional findings are anticipated to be available in early 2020.

Bring Your Brave Campaign Updates and Future Ally Moehring

Health Communication Specialist, Katmai Inc.

Ms. Ally Moehring is a health communication specialist with Katmai Resource Management. She has been contracted to assist with the Bring Your Brave Campaign communication component. She presented on some of the recent changes and the future direction for the campaign.

One of the new components to the campaign is the Health Care Provider website. It corresponds with the CME and educates providers about breast cancer in young women. Corresponding resources also are available, like downloadable PDF tip sheets. Recently, an educational video was created to inform providers on the risk factors for early-onset breast cancer, ways to lower risks through lifestyle choices, medical interventions, and genetic counseling.

One of the goals is to reach more young women by connecting with them where they are. New ways to reach this population are always being explored. One of the recent outreach efforts includes a podcast series. This podcast utilizes stories from young women who have been affected by breast cancer to encourage other women to engage in discussions, inspire, and educate about risks. Women were asked to focus on one specific area. The series is called My Motivated Moment.

The video series launched in 2015. One of the series is about sisters Emily and Caroline. Their mother is a survivor, and the video follows the women as they explore their risks. Both found they were BRCA positive, but their action pathways are different. One decided to have a prophylactic mastectomy, while the other decided to wait because she is young, has time, and has good medical care. The goal is to encourage women to know their risk.

Another goal of the video series is to show women that they are not on their own by letting them hear and witness how others are dealing with some of the same challenges. One of the video series is about a young lady named Charity, a breast cancer survivor who was diagnosed at the age of 27.

Educational videos are also available. One of the videos is avatar-based. They are conversational, virtual, and scripted, as well as instructional in tone. The other is the Ask the Expert series. Drs. Richardson and Fairley provide answers to frequently asked questions. The videos dispel myths and provide accurate information regarding risks.

The Bring Your Brave campaign always seeks new ways to reach its target audience. One way is through a collaboration with Hollywood, Health and Society. Through this organization, CDC works with writers in the television and film industry to ensure the health messages that are inserted into scripts are truthful and are portrayed accurately. The organization will reach out to DCPC when they have a storyline that is related to breast cancer, most often breast cancer in young women, to gain advice before scripting and filming. DCPC has consulted on the 90210 reboot, Parenthood, and Grey's Anatomy. In March 2017, for Grey's Anatomy, DCPC provided subject matter expertise, information for scripting, and a PSA that broadcast at the end of one of the airings where a patient had inflammatory breast cancer. The PSA gave the different signs and symptoms for that particular type of breast cancer. The program also provided a social media content toolkit for show runner, writers, and actors to use as they live-tweeted throughout the episode.

The most recent work of the collaboration is a show called The Bold Type. Hollywood, Health and Society approached DCPC two years ago to utilize subject matter expertise for scripting a part of their first season. The show is about three women in their mid- to late 20s who work at a magazine publishing firm. The show follows their friendship. In an episode titled The Breast Issue, one of the characters is dealing with her family's history of breast cancer. The character writes an article about risk in young women, and as she is writing the article, she battles with her own decision of whether to be tested for her risks. The character tests positive and the show follows this character through all the other decisions she has to make and the challenges she encounters, like fertility issues and dating. When the episode aired for the character who tests positive, there were 98,805 impressions, 1,909 engagements, 394 retweets, and 445 likes.

One of the future aims of the Bring Your Brave Campaign is to deal with the knowledge gaps and to clear up misinformation in several areas like male breast cancer and direct-to-consumer testing. Another goal to address the knowledge gaps that exist for providers, like ways to address risks and the importance of encouraging women to know their risks. Research shows that knowledge gaps still remain related to areas such as:

- Lifestyle and Risk Reduction
- Disparities
- Direct-to-Consumer Genetic Tests
- Managing High Risk
- Recurring questions/themes like:
 - Pap test does not screen for ovarian cancer
 - Ovarian cancer risk and BRCA

- Environmental concerns about breast cancer risk, like e.g. bras

Tools are being developed to assist with provider education. CMEs have always been shown as a way to reach providers, particularly nurse practitioners and physician assistants. Therefore, the CME for Medscape is being refreshed and updated. Also, since time is a precious commodity for physicians, an online risk assessment tool is being developed that will give providers a quick and straightforward assessment for their patients.

Comments from the ACBCYW:

- Share tear sheet tool with the Committee so that it can inform the working group exercise.
- Consider adding the risk factors for extremely dense breast tissue. Those patients need a referral to a higher-level provider that is not necessarily in Epic.
- Tool should advise not only when to refer a patient, but also whom to make the referral.
- Coupling restricting alcohol consumption into weight management makes women more receptive.
- Start with a positive approach to allow the conversation to go deeper and progress into some of the harder topics. Use the educational process to reward where they are. For example, you are already getting 30 minutes or more of exercise every day; look at the profound impact that can have on your breast cancer risk.
- Consider making a web page regarding myths and facts around direct-to-consumer testing. Some examples of topics to add are Pap smears screening for ovarian cancer, losing insurance based on direct to consumer testing, etc.
- It is important to share with women ways to take their health outcomes into their own hands.
- From a marketing perspective, the knowledge is power message seems to work better for this space. Fear holds people back from learning the very valuable information that can save their lives.
- Knowing that there is a community out there or having stories that can be alluded to helps brings comfort and makes the women not feel isolated. It gives a sense of empowerment and is as important as the educational component because it removes the sense of fear.

DIRECT-TO-CONSUMER TESTING AND EARLY-ONSET BREAST CANCER

Sadie Hutson, PhD, RN

Professor & Assistant Dean of Graduate Programs
The University of Tennessee, Knoxville

Genetic assessments and testing for hereditary cancer has become increasingly complex over the years. As more testing options surface, more challenges arise with interpreting the complexity of the results. In 2007, the first direct-to-consumer (DTC) tests did not use comprehensive sequencing technology, but rather single nucleotide polymorphisms (SNP) variations in a single base pair. Later, next-generation sequencing was introduced, which is the reading of an entire gene in detail. In 2013 and 2014, multigene panels became available. They provided a stepwise approach to the sequencing order, determining next steps when receiving negative results, and dealing with insurance coverage issues. In 2018, the Food and Drug Administration (FDA) approved the first DTC test for BRCA mutations.

DTC testing is genetic testing that consumers can purchase and interpret without necessarily involving a health care provider. These tests can be bought online or through stores. The consumer submits a DNA sample and receives their results directly from a secure website or a written report. On March 6, 2018, the FDA granted the first marketing authorization to 23andMe for DTC testing for three BRCA1 or BRCA2 mutations that will identify women at increased lifetime risk of breast cancer. These tests identify the 185delAG variant in BRCA1, the 5382insC variant in BRCA1, and the 6174delT variant in BRCA2. These founder mutations are found in approximately 2% of women in the Ashkenazi Jewish population, but more than 1,000 mutations exist in BRCA genes.

In general, DTC tests for non-medical, general wellness, or low-risk medical purposes are not reviewed by the FDA. On the other hand, the DTC tests for moderate- to high-risk medical purposes are generally reviewed for:

- Analytical Validity: Whether a test can accurately and reliably measure what it claims to be capable of measuring.
- Clinical Validity: Whether the measurement is predictive of a certain state of health.
- Claims about the test and how well it works: What a company says about their test and how well it works.

The table below outlines the different types of tests as well as the FDA's review level for the test. More in-depth information can be obtained at www.fda.gov/medical-devices/vitro-diagnostics/direct-consumer-tests.

Type of Test	FDA Review
Carrier Screening Tests	Exempt from pre-market review, but must follow specific requirements
Genetic Health Risk Tests ✓	Required to obtain FDA clearance prior to first test
Pharmacogenetics Tests ✓	Required to obtain FDA clearance (none currently approved)
Cancer Predisposition Tests ✓	Required to obtain FDA clearance prior to first test
Low Risk General Wellness Tests	Not reviewed
Ancestry Tests	Not reviewed

The 23andMe test costs \$199. With this test, the consumers submit a salivary swab. The results take 6 to 8 weeks to be returned. For a little more money, the consumer can obtain a higher grade of information and services. For example, the Color test costs \$249. It examines 30 genes through a salivary sample. Before the test is ordered, there is a level of physician review, and genetic counseling is offered. The same is true for Invitae-Proactive Test, which costs \$250 and tests for 60 genes.

Dr. Hutson also provided the table below, which outlines the U.S. Preventative Services Task Force’s (USPSTF) recommendations regarding direct testing. These recommendations stand in contrast to the FDA approval for marketing tests such as 23andMe.

Population	Recommendation	Grade
Women who have family members with breast, ovarian tubal, or peritoneal cancer	The USPSTF recommends that primary care providers screen women who have family members with breast, ovarian, tubal, or peritoneal cancer with one of several screening tools designed to identify family history associated with increased risk of mutations in BRCA1/2. Women with positive family history should receive genetic counseling and, if indicated, genetic testing.	B
Women whose family history is not associated with an increased risk	The USPSTF recommends against routine genetic counseling or testing for women whose family history is not associated with an increased risk of BRCA1/2 mutations.	D

There are key criteria for hereditary cancer risk evaluation, when examining personal history. They include:

- Female breast cancer diagnosed at 50 years of age or younger
- Triple-negative breast cancer diagnosed at 60 years of age or younger
- Two or more primary breast cancers
- Invasive ovarian or fallopian tube cancer, or primary peritoneal cancer
- Male breast cancer
- Any HBOC-associated cancers, regardless of age at diagnosis, and of Ashkenazi (central or eastern European) Jewish ancestry
- Breast cancer and either a relative with breast cancer diagnosed under 50 years of age or ovarian cancer, or two relatives with breast, prostate, and/or pancreatic cancer, diagnosed at any age
- Metastatic, regional, or high to very high risk clinically localized prostate cancer
- BRCA pathogenic variant identified from tumor genomic analysis, regardless of tumor type

The criteria are developed in concert with the National Comprehensive Cancer Network (NCCN), the National Society of Genetic Counselors (NSGC), and the American College of Medical Genetics (ACMG).

Dr. Hutson provided the definitions of genetic and genomic. Genetics is the study of the genes that people inherit at birth. Genomics looks for alterations anywhere in the genetic code, as in the case of tumor testing. She went on to review the key criteria for hereditary cancer risk evaluations for individuals with a family history. They were:

- A pathogenic variant in BRCA1 or BRCA2 in a biological relative, usually a first- or second-degree relative.
- At least two individuals with breast cancer primaries on the same side of the family, with at least one diagnosed at 50 years of age or younger.
- A first- or second-degree relative with any of the following: breast cancer =45 years, ovarian cancer, male breast cancer, pancreatic cancer, metastatic prostate cancer, or =2 breast cancer primaries in a single individual or on the same side of the family with at least one diagnosed =50 years.
- Family history of three or more cancers linked to hereditary cancer syndromes.

There are some major concerns around DTC testing for breast cancer. The three mutations in the 23andMe test occur in 2% of women of Ashkenazi Jewish descent but occur rarely among other populations (0% to 0.1%). In addition, the negative results of DTC testing are not definitive; and additional testing may be needed if there is a clinical indication of increased risk. Moreover, clinical decisions about DTC test results should not be made until results are confirmed in a clinical lab on a new specimen. Lastly, testing may appeal to and be overpromoted to low-risk populations.

In April 2019, a study led by investigators at Invitae, Dana-Farber, Yale, and Georgetown was presented at the American College of Medical Genetics and Genomics. The revealed the preliminary results regarding the limited clinical utility of DTC tests in a sample of 125,000 individuals. Of those individuals, 119,000 were referred because of a personal history and 5,200 without personal or family history. There were 100 individuals who were referred for confirmatory testing after they had received a positive DTC test result. The ultimate goal is to study 200,000 individuals.

For the women who had an indication for testing (either personal or family history), 11% had a pathogenic mutation (n=13,000). Of those individuals, 4,700 had a pathogenic mutation in BRCA1/2, but only 12% had one of the founder mutations (n=564). Nineteen percent of the women who self-reported they were Ashkenazi Jewish had a mutation other than the three founder mutations. Only 12% of individuals who had no personal or family history were found to have a mutation in the three founder mutations; and 88% had a different mutation altogether.

In the 100 patients who were referred for confirmatory testing, the lab was only able to confirm a positive result in 50% of individuals. This absolutely raises questions regarding false positive results. Overall, DTC missed almost 90% of BRCA mutation carriers and it missed almost 20% of BRCA mutations in those who self-reported Ashkenazi Jewish descent.

In another recent study, Ambry Genetics analyzed samples from which other DTC companies had reported genetic variance. The raw data finding showed that 40% of variance in a variety of genes were false positives. In addition, some of the variance were designated with an increased risk classification in the DTC report, which were classified as benign according to Ambry's research.

Another piece of relevant information came from the European Breast Cancer Council. In 2018, it published a manifesto on genetic testing among healthy people to establish risk amid fragmented regulatory standards. A call was sent out to policymakers, health care professionals, and advocates to ensure genetic testing is carried out according to EBP guidelines.

DTC polygenic risk products are also available in the market. They examine a multitude of low-risk mutations. The scores are different from diagnostic tests because they measure the risk of developing a disease. The prognoses are made using a combination of data from genome lab association studies, personal and family history data, and risk algorithms. These are being investigated as a possible add-on to risk prediction models and could be informative where there are no high-risk mutations in people with a family history of breast cancer. Myriad recently launched one of these products called Risk Score. The *Journal of the American Medical Association (JAMA)* recently published a review of polygenic risk products, as well.

Supporters of DTC testing cite several advantages such as patient empowerment, non-invasive collection of samples, increased accessibility to BRCA testing, increased awareness of diseases that have a genetic component, increased patient engagement which may lead to improved genetics literacy among consumers, and prompts to adopt healthy lifestyle changes. However, some disadvantages should be noted. A DTC test containing three founder mutations does not improve access to those with barriers to obtaining genetic risk assessment and testing. Test availability does not provide assurance that health outcomes will change for patients. There can be unintended psychosocial consequences, and important decisions about treatment and disease management may be made based on incomplete, inaccurate, or misunderstood information. Lastly, genetic privacy may be compromised if companies use results in an unauthorized way.

DTC tests have implications. For patients, the test results can often be confusing and have conflicting information from multiple companies. Communication with providers regarding testing and subsequent results may not happen at all. The costs of genetic testing—DTC or provider-initiated—are not well-understood. Lastly, family implications can result from testing.

In the case of providers, the implications for patients are inherently the implications for providers. Also, the landscape of genetic and genomic testing is evolving rapidly. Moreover, providers of all types must be informed about all of these tests and take the time to seek resources for their practices and patients.

To overcome the challenges and questions surrounding DTC, there has to be balance between patient autonomy, clinical utility, and ensuring patient safety, as well as technological innovation. Success can only be achieved if there is an understanding of how technology impacts patients. It is difficult to know if DTC tests will yield benefits to society, but in the meantime, health professional organizations, patient advocacy groups, and others strongly recommend that people considering genetic testing for breast cancer, including DTC tests, talk with health care providers about the reasons for undergoing testing and what the results could mean for their personal and family members' health.

Comments from the ACBCYW:

- The American Indian and Alaska Native communities have expressed concerns about what the DTC companies would do with genetic testing, how the results are stored, and how they are used in the future. These communities are also fearful of medical and research testing. They need to be assured that proper stewardship of the genetic information is being utilized.
- There must be precision in the terminology utilized around genetic testing; for example, saying that genetic testing is a form of screening.
- Thought needs to be given on how to fill the gaps in knowledge around genetic and genomics.

- There should be an education and messaging campaigns regarding DTC testing for providers and customers. It is critical to have precision in the language used in this space.

ACBCYW OPEN DISCUSSION

The ACBCYW engaged in an open discussion about the information shared during the course of the day to identify topics that need more dialogue or need to be elevated to the attention of a working group. There are currently three working groups: Provider, Survivorship, and General Risk Assessment and Management. These are carryover working groups from the last committee meeting. The plan is to lay out the work for the current working groups or new working groups, if needed, to work on in the coming months. A few comments were heard.

- Within messaging, accessibility is important. Creating a tool that is online may not be the most savvy and realistic methodology for the care settings.
- Educate physicians and patients regarding genetic testing of girls under the age of 18 and the guidelines that apply for that age group.
- Bring insurance companies up-to-date on the current testing criteria and possibly create a guideline for insurance providers. Dr. Fairley talked about one of their grants that had an insurance provider education component. She will facilitate an opportunity to share the information that has emerged in a future meeting.

Below are the Hot Topics identified.

- Fertility
- Survivorship
- Provider Education**
- Economics/Special Populations/Topics
- Education HCP regarding testing guidelines
- Mental health for all the above topics
- Sexual health
- Genetic testing/genetic messaging related to DTC**
- Messaging to subgroups**
 - Age**
 - Demographics**
- Language used/empathy**
 - Medicine**
 - Patient and provider communication**
- Accessibility**
- Provider resources

- Educate HCP see phone for remainder
- Add CMS under access portion
- Mental health implications
- Disparities**
 - Race**
 - Sexual orientation**
 - Age**
 - Geography**
 - Cultural implications**
- Positive framing of messages**
- Access to care for genetic testing including CMS, etc.

Highlighted text relates to messaging and communication.

Not enough members were present to make a vote on the list of topics, but Dr. Fairley asked the Committee to do some further thinking on the list to frame the discussion for day 2. Messaging appears to be one of the highest priority groups. If the ACBCYW decides that it wants a workgroup for messaging, it will need to develop a charge for the working group that has to be accomplished by the next meeting.

Another important priority was mental health. The Committee will need to decide if this should remain a part of the Survivorship Workgroup, as in the past, or if it needs to be its own group. A copy of the previous minutes for the Survivorship Workgroup were distributed to the Committee. Below is a list of issues developed by the Committee pertaining to this area.

- Provider support/ed
 - Primary care
 - Oncologist
 - OB/GYN
- Patient support/ed
- Acknowledge different diagnoses like PTSD, depression. etc.
- Awareness and self-advocacy
- Safe space conversation
- Follow-up care concerns
- Familial support-counseling
 - Care giver support
- Fear of recurrence
- Mental health for previvors
- Pre-existing mental health concerns
- Maternal mortality – African American communication lessons learned

An additional topic identified was prevention and early detection screening. A short list of issues was created and is listed below.

- Prevention and Early Detection/Screening
 - Chemoprevention
 - Vaping and e-cigarettes concerns (emerging concerns)
 - Legalization of marijuana (emerging concerns)

PUBLIC COMMENT

Ms. Amanda Winslow is a technologist at a small health care facility. One of their biggest challenges is getting young women to come in for screening, and this is mainly due to confusion in guidelines when dealing with insurance companies. She wondered if there was any cohesion between different society or regulation guidelines regarding when screening should begin and ways to deal with insurance companies when comes to screening, particularly for women at high risk.

Dr. Fairley and a couple of ACBCYW members responded there has been no feedback regarding rejections for individuals who are 40 years old and older. The NCCN guidelines covers high-risk individuals with a first-degree relative 10 years back from the year of their diagnosis. It would be screening. But, they felt, NCCN covers elevated risk for abnormal breast lesions, biopsies, or first-degree relatives. That guideline can be accessed online and could be used when dealing with the insurance company.

SUMMARY AND NEXT STEPS

Dr. Fairley gave a brief review of the Day 2 activities. With no further comments, the meeting was adjourned at 5:01 p.m. EST.

TUESDAY, AUGUST 20, 2019

DAY 2: WELCOME AND ROLL CALL

Temeika Fairley, Ph.D.

Designated Federal Officer, DCPC, CDC

Dr. Fairley conducted roll call and confirmed that the 13 voting members and *ex-officio* members (or their proxies) in attendance constituted a quorum for ACBCYW to conduct its business on Tuesday, August 20, 2019. She called the proceedings to order at 8:12 a.m. EST.

REVIEW AND HIGHLIGHTS

Elana Silber

Sharsheret

ACBCYW Committee Chair

Ms. Silber provided a quick review of some of the foremost topics covered on Day 1 of the meeting. One of the topics mentioned most frequently was messaging. All of the topics presented require careful consideration when creating messages. She asked the committee, after hearing the day's presentation, if a working group should be created to solely examine this area, or should this be incorporated into the already existing working groups. Considering the population of interest, changes in science, emergence of genetics, etc., messaging should be one of the chief priorities.

Another topic of importance is mental health. Many aspects are impacted by mental health, like healing and wellness. There are many opportunities to incorporate this topic into the work of the ACBCYW.

She also felt as a group the ACBCYW indicate the overall priorities for its work, which will help to make an impact on any of the paramount topics identified.

UPDATES FROM THE FIELD

Arin Ahlum Hanson, MPH, CHES

Associate Director, Outreach and Partnerships

Living Beyond Breast Cancer

Ms. Arin Ahlum Hanson is the Associate Director of Outreach and Partnerships at [Living Beyond Breast Cancer](#) (LBBC), which is a national nonprofit. Its mission is to connect people with trusted breast cancer information and a community of support. It fulfills its work through a number of programs and services online, in print, by phone, and in person. In today's presentation, she highlighted one of the organization's newer programs, Survivorship Series for Young Women Affected by Breast Cancer.

The Survivorship Series trains oncology nurse navigators to implement a four-part group patient education program in their cancer centers. The nurse navigators are known as program leaders. The series focuses on survivorship concerns for women that have been diagnosed before age 45. The program is through LBBC's Young Women's Initiative, which is funded through the CDC Cooperative Agreement DP14-1408 (2014 to 2019). The program will continue with the newly awarded CDC Cooperative Agreement DP19-1906 (2019 to 2024). The two main program objectives are to 1) increase the program leaders' knowledge of the survivorship topics covered in the curriculum and their confidence to implement the program, and 2) increase the program participants' knowledge of survivorship topics and confidence to make behavioral changes to increase their quality of life after breast cancer.

The program was started in 2017, when LBBC engaged Lori Ranallo, RN, MSN, ARNP-BC, to assist in the development of the curriculum. Ms. Ranallo has operated a breast cancer survivorship clinic for many years, and serves as a consultant for the medical and content piece of the Survivorship Series. The first program leader cohort was trained in April 2018, where 11 nurse navigators completed training. The second cohort was trained in February 2019, with 15 individuals trained as nurse navigators.

The series was started for several reasons. Very few cancer centers offer patient education programs that address these survivorship topics for young women. Also, some health care providers report feeling unprepared to adequately address these patients' needs. The series builds off of LBBC's strengths of working with health care providers, young women affected by breast cancer, and implementing training programs. In addition, the program leverages the relationship the patient has with their nurse navigator and cancer center to connect them to LBBC's tailored resources for young women. And lastly, the series engages young women who are less likely to seek out LBBC on their own.

One of the important parts of the program is the independent external evaluation. In January 2018, the Survivorship Series Program was selected by the CDC to have an independent external evaluation by Oak Ridge Associated Universities (ORAU). The ORAU Evaluators were tasked to identify and assess the effectiveness of HCP education resources, which provide information on early onset breast cancer. An environmental scan was conducted and LBBC's Survivorship Series was one of the only HCP education programs focused on young women affected by breast cancer.

The main component of the Survivorship Series Program is an in-person program leader training, which is 20 hours in length. It provides in-depth education on the medical and psychosocial content covered in the series, facilitation skill building, and marketing and implementation tools. Once trained, the program leaders are then tasked to implement the four-part series at their home cancer centers within five months. These centers also support the marketing and implementation of the sessions. LBBC provides ongoing support through monthly check-in calls, an Online Resource Hub, and a closed Facebook group for program leaders. The LBBC staff provides ongoing technical assistance through phone and email communication.

Below are the topics covered for Survivorship Series Sessions in year one:

1. Let's Talk About Sex and Breast Cancer
2. Hot and Bothered: Coping with Early Menopause
3. Stay Alert: Managing the Long-Term Side Effects of Breast Cancer Treatment
4. More You Know: Understanding Your Genetic and Cancer Risk

After feedback from the first year, it was decided to restructure the series for year two. One feedback was that starting with the sex and intimacy conversation at the beginning was a little overwhelming. Participants needed an opportunity to get to know one another before a discussion of that nature could take place. Also, the last session was reformatted into self-care after breast cancer. There is still some genetic risk component in that session as well as risk for developing secondary cancer after breast cancer; however, it also contains information on adopting healthy habits and holistic wellness. Therefore, the series has been rearranged to the order below.

1. Hot and Bothered: Coping with Early Menopause
2. Stay Alert: Managing the Long-Term Side Effects of Breast Cancer Treatment
3. Let's Talk About Sex and Breast Cancer
4. Self-Care After Breast Cancer

Each session is generally an hour to an hour and 15 minutes of formal content and facilitated discussion. The program leaders hold the session in two-hour blocks to allow for networking and conversation. A suite of materials were developed to support each session. The programs are provided with the following resources:

- Slide decks with discussion prompts and online videos
- Worksheets
- LBBC mailing list sign up forms
- LBBC care boxes or gifts
- Marketing templates
- Participant evaluations
- Program leader session reports

So far, 26 oncology nurse navigators have been trained, and all have implemented the series successfully. The program leaders represent 26 cancer centers, with the majority of them being community cancer centers.

Since the Program Leaders know their patient community best, they are given autonomy to make many programmatic decisions. The program leaders select the timing and flow of the program, as well as enhance the content of the series by including guest speakers, like yoga instructors and pelvic floor physical therapists. They also create resource sheets that list LBBC resources and highlight local resources specific to the topic discussed.

The series has a robust evaluation plan, which has produced helpful feedback to be utilized going forward. The program leaders complete a Pre and Post Training Assessment and Post-Training Evaluation. They also complete session reports and submitted their modified materials after each session. In addition, the leaders disseminated evaluation forms to each participant to complete by hand at each session. One-hour interviews were conducted over the phone with all 26 program leaders and a subset of program attendees yielding 33 participants from 20 of the 26 sites. Lastly, LBBC staff was also interviewed.

The pre and post assessment showed increase knowledge gains on all survivorship series topics as a result of the in-person training. The program leaders reported high levels of satisfaction with the training.

The program reach was relatively the same for years one and two. The total attendance across the eleven sites for year one ranged from 68 to 111 individuals. For Year 2, the total attendance ranged from 81 to 123 for the 15 programs. In total, there have been approximately 700 attendees over the past 2 years. This counts attendance, not unique participants.

Ms. Hanson went over some of the evaluation findings. Participants favorably reviewed the content of all four sessions. The majority of participants strongly agreed with the following statements:

- I feel this session was helpful to me (79%)
- I feel the length of the session was appropriate (78%)
- I feel the instructor showed a thorough knowledge of the topic (76%)
- I feel the instructor answered questions effectively (83%)
- I feel the materials were easy to understand (84%)
- I feel that I am not alone in my experience with breast cancer (79%)

There are some areas for improvement. Only half of participants reported becoming more familiar with LBBC as a result of the program, which was gathered by the responses to the following questions:

- I am familiar with Living Beyond Breast Cancer as an organization (53%)
- I am familiar with LBBC resources (48%)

This indicates that LBBC should focus more on training the program leaders to serve as more effective ambassadors for LBBC and develop a more effective post-program engagement strategy. This has been addressed through a series of emails.

In the interviews, participants were asked why they attended the program and the majority said they were attracted to the emphasis on young women. They also indicated that they appreciated the connections they made with others; the information they learned from group; and the opportunity to listen to others facing similar situations. Many of the women offered specific examples of information they learned in each session during the interview. They reported “feeling not alone,” “affirmed,” and validated by other participants.

As a result of the feedback received thus far, there have been some significant changes made to the 2019 program. As previously noted, the order of the series sessions have been reframed. Also, program leaders with more prior experience facilitating in-person programs were recruited. The facilitation skill building portion of the training has been increased from one hour to four hours. In addition, a local resource templates was created for the program leaders to use and modify to their unique settings. A Survivorship Series landing page has been created specifically for the program on the LBBC site. Traffic to the page is advertised through emails and the in-person program. The landing page has more details on the topics covered in the series and familiarizes visitors with the other resources offered by LBBC. In addition, there is a multi-touch email engagement strategy for individuals that signed up for the mailing list. YWiConnect, a text service, has been integrated and will provide updates on any new programs for young women. Lastly, LBBC name tags were added to the list of materials.

The year two evaluation is forthcoming so there will be more changes, but thus far, proposed changes for 2020 include:

- Develop a session for young women living metastatic breast cancer. Rename the program to be more inclusive to the metastatic experience.
- Increase cancer center buy-in by inviting all key personnel from participating institutions to attend a webinar that provides an overview of the series content and reviews strategies on how to support and promote the program.
- Better align program with National Accreditation Program for Breast Centers (NAPBC) accreditation requirements.
- Pursue nursing CE accreditation
- Modify evaluation plan and evaluate potential institutional change elements of the program.

In conclusion, the pilot evaluation conducted by ORAU showed that the Survivorship Series was an impactful program for program leaders and participants. The program successfully provided a high-touch supportive educational experience to over 300 people in the last two years. The model also demonstrates that engaged health care providers can be effective vehicles for deepening the LBBC's reach in areas of the country where LBBC has a limited presence.

Julia O'Hara, MPH

Program Manager, Gynecology Practice
American College of Obstetrics and Gynecology

Ms. O'Hara is the Program Manager for American College of Obstetricians and Gynecologists (ACOG). She provided an overview on the work of ACOG and presented their Early-Onset Breast Cancer Education for Women's Health Care Providers Project.

ACOG is a membership organization of 64,000 members. The organization is dedicated to the advancement of women's health care and the professional and socioeconomic interests of its members through continuing medical education, practice, research, and advocacy. This mission aligns with the Bring Your Brave Campaign. There is also access to a network of women's health care providers, which makes the organization a suitable partner for CDC's Early-Onset Breast Cancer Provider Education Initiative.

ACOG is funded by a CDC cooperative agreement. Dr. Temeika Fairley serves as the organization's leader and technical monitor. The Early-Onset Breast Cancer Education for Women's Health Care Providers Project is the provider-focused branch of CDC's Bring Your Brave patient education campaign. The target audience for the program includes several types of women's health care providers, such as OB/GYNs, nurses and nurse practitioners, physician assistants, internists, and allied health professionals.

The purpose of the project is to explore innovative ways of educating the various types of health care providers about early onset breast cancer. There are three phases of the project. The first is the formative research phase, which includes literature review, an evidence review conference, and stakeholder input. The second phase is development of provider education materials. These are narrative-focused, video-based CME/CEU accredited e-modules. The final component of the project is the dissemination of the information and education materials. Marketing and dissemination is tailored to each unique provider community.

Ms. O'Hara provided the graphic below to explain the formative research process. The components combine to help the organization achieve its goal of educating providers and improving outcomes at the population level.

Formative Research Process

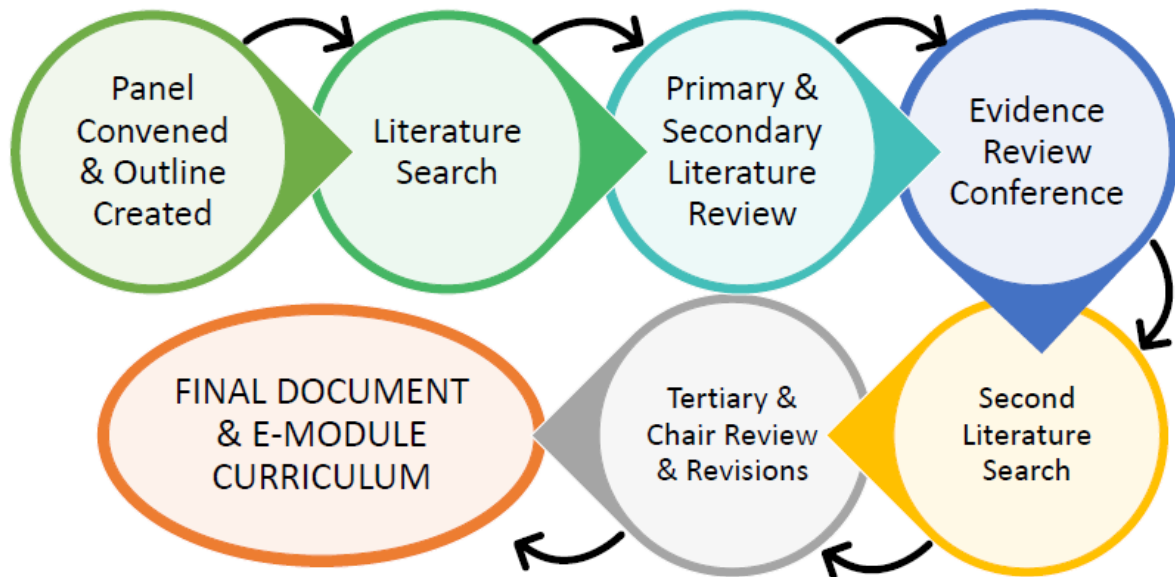


Figure 3. The Formative Research Process

The creation of the project began by recruiting a panel of physicians from the Society for Academic Specialists in General Obstetrics and Gynecology (SASGOC) to perform an evidence review. This panel in concert with ACOG's staff and a variety of other stakeholders identified ten topics and created Problem/Patient/Population, Intervention/Indicator, Comparison, Outcome (PICO) criteria that would lead to an outline for the literature review. Each topic was examined through the PICO framework.

The ACOG Resource Center searched for references. All the literature was organized by level of evidence. The published guidelines and references were categorized separately. The panelists expanded the literature search when necessary to ensure all available evidence was captured.

Members of the panel were assigned sections of the outline to conduct a primary literature review draft. Afterwards, each were tasked to review one of their colleagues' sections for a secondary review.

The Evidence Review Conference was a two-day, in-person conference, where a broad group of chief stakeholders and breast health experts provided their extensive feedback and recommendations. Comments were incorporated into the evidence review summary. A second literature search was conducted to ensure all information was captured in light of the feedback received during the conference. The draft was then reviewed for a third time overseen by the panel chair presided, and the revisions and edits were conducted. The final document is the bases for the e-module curriculum.

Below are the workgroup stakeholders. They provided a variety of perspectives. They attended the Evidence Review Conference and invited to provide written and verbal feedback on the literature review and during the presentation. Stakeholder feedback and input was incorporated throughout every phase of the project. This will continue to be the process as work moves forward. SASGOG will continue to serve as the content manager.



Figure 4. Workgroup Stakeholders who Participated in the Creation of the E-Module

Several high-level themes were captured in the formative research. These insights came from 238 ACOG members and in-depth interviews with 11 providers from various designations and specialties. When it comes to early-onset breast cancer education, providers have a variety of needs. They include the follow:

- Risk-assessment tools
- Risk-reduction strategies
- Risk communication
- Genetic risk factors
- Health disparities

The preferred education delivery methods include evidence-based clinical guidance; CME/CEU-accredited e-module; and patient education materials. Other provider challenges identified included:

- Need for evidence-based clinical guidance
- Need for consistent guidance across providers/specialties
- Need for efficient and effective evidence-based risk assessment tools
- Gaps in evidence specific to EOBC (18-45 age range)

These challenges were also validated by the information gathered in the literature review.

As a result of these findings, ACOG will publish a literature review outlining current evidence and recommendations, as well as develop CME/CEU-accredited e-module to operationalize evidence-based best practices. Ms. O'Hara presented the outline of the e-module curriculum. All of the education needs identified by providers during the formative research phase are covered in the e-module. It is broken into two sections.

Part 1: Risk Factors for Early-Onset Breast Cancer

- Genetic risk factors
- Dense breasts
- Family history
- Prior history

Part 2: Assessing and Mitigating Risk for Early-Onset Breast Cancer

- Health disparities
- Tools for assessing risk for early-onset breast cancer
- Communicating risk to patients
- Understanding genetic counseling and testing
- Risk reduction measures
- Special considerations in early-onset breast cancer

The module will utilize narrative-based videos exploring patient-provider communication and will model conversations.

Ms. O'Hara explained how all of this information will be utilized. The Bring Your Brave Campaign equips young women with the tools needed to take control of their health and talk to providers about their risk for early-onset breast cancer. The provider education will equip the providers to meet the needs of these patients and assess their risks without bias. One way to accomplish this goal is to start the conversation early and to treat family history as a symptom.

Since the majority of early-onset breast cancer are detected outside of the clinical environment, it is imperative for providers to start the continuum of care earlier including conversations about breast health and risk factors. The majority of cases of early-onset breast cancer are detected by women themselves and have a higher mortality rate.

Most providers will say that they already know how to take a family history, but asking the right questions to get the most thorough and accurate details possible is of great importance. Providers have to know how to deal with patients who do not know their family history, may be adopted, or are reluctant to talk. It is also important for patients to

understand, when they are talking to a provider, they should consider both history of cancer in female and male relatives.

ACOG is working to meet providers where they work and learn. One way this is accomplished is by attending a variety of in-person meetings to meet providers and raise awareness of the upcoming educational opportunities and resources. This is done both before the CME launches and after. Visual concepts of an evolved Bring Your Brave brand are being created and will be tested among the provider community. A marketing firm is being utilized to develop messages that speak specifically to providers. Paid digital ads and partnerships will also be vehicles for reaching this target audience. The marketing efforts will leverage multiple channels, include highly targeted messages for different provider audiences, and be tailored to each groups' unique needs.

Going forward, ACOG has developed a to-do list of activities it will accomplish in the remainder of 2019 and early 2020. They are as follows:

Remainder of 2019:

- Attend various annual meetings to raise awareness of upcoming educational materials
- Develop and produce e-module
- Develop marketing campaign

Early 2020:

- E-module goes live
- Integrated marketing campaign
- Measurement and reporting of metrics

Comments from the ACBCYW:

- The American Academy of Family Physicians (AAFP) has a tool for providers which helps to build a culturally competent environment. It includes a guidance document that teaches ways to modify a physician's practices systemically so that it is conducive to respond to special populations. Consider a way to integrate this tool into the health disparities component of the project.
- Ms. Sue Friedman volunteered to assist with integrating information like intermediate rest genes and panel testing. Her organization works with this population of patients. CDC should take an initiative approach to gather more information regarding these mutations to fill gaps in provider and patient knowledge.
- The references that were used to create the learning module, like the literature search, would be very relevant for the potential working groups. Considering making them available to the ACBCYW members.

- Ms. Lindsay Avner from Bright Pink has a medical professional initiative that educates women health providers. They also have to online modules with CME approval. She welcomes the opportunity to partner with ACOG.

ABCYW OPEN DISCUSSION

The ABCYW moved into an open discussion. Before beginning the dialog, Ms. Silber reviewed the current workgroups. They are Risk Assessment and Management; Provider; and Survivorship. The groups were created after the previous ABCYW meeting. Minutes and a report of the work achieved in those groups were made available to the committee. The objective is to determine if the workgroups should be revamped, amended, or dissolved in light of the information heard during the meeting.

The General Risk Assessment and Management Workgroup is co-chaired by Dr. Nicole Saphier and Ms. Joyce Tannenbaum Turner, MS, CGC. The charge of the workgroup is to discuss and identify the current state of affairs regarding breast cancer risk assessment messaging to young women and to identify areas of concord and discord related to these messages. This group worked on the following topics:

- Determining what is considered high risk
- DTC genetic testing (challenges, opportunities, next steps)
- Genetic testing panels
- Other non-BRCA genetic mutations for diverse populations
- Coverage for mammograms and other screening
- Coverage for BRCA+ women choosing IVF for PGD

The Provider Workgroup's chairs are Dr. Kenneth Lin and Ms. Lindsay Avner. The order for this workgroup is to review activities completed by the previous membership; gather new background information to further improve provider behavior, education, and training regarding breast cancer in young women; and to advise the ACBCYW on prioritizing and supporting ongoing programmatic efforts in the future. This group discussed:

- Which health care professionals should we target;
- Topics for education in addition to genetics;
- What existing provider education programs are most effective and how can they be adapted to new audiences; and,
- Expanding dissemination of provider education programs.

The Survivorship Workgroup's leader is Ms. Elissa Thorner. Ms. Anna Crollman and Ms. Carletta Cunningham serve as the group's committee members. The charge for this

group is to review and identify the current state of affairs regarding breast cancer survivorship care for young women with inclusive of all stages of disease with special attention to patient-centered care and health equity, and advise the Committee to meet needs and address gaps. A presentation of their work was distributed to the ACBCYW. At the time of their work two years ago, the areas below were identified as places where more focus was needed:

- Review existing survivorship programs for YBCS under 45 to identify gaps in information.
- Identify long-term survivorship issues for women diagnosed under 45 and now living beyond 45.
- Advocate for fertility treatments coverage for survivors.

Comments from the ACBCYW:

- The Risk Assessment and Management Workgroup appears diverse in its charge. DTC genetic testing, genetic panels, anything genetic in nature is a huge undertaking and therefore should be its own workgroup.
- Although CDC has a plethora of wonderful materials created for providers, it is rarely the go-to website for physicians. It is important to focus on the key areas that are integrated with organizations like the National Accreditation Program for Breast Centers (NAPBC) and the American Society of Clinical Oncology (ASCO) on the markers that physicians have to meet. Determine the gaps on those sites.
- Survey the work already occurring in the provider space to determine efficacy of their efforts. What is happening now? Who is doing it? Who is doing it well? Are there large organizations that are performing the work well? Are there EBIs in the provider space that are effective? The committee can take the findings and determine what expertise can be applied to the different areas of the ACBCYW's work and begin to think in a modular fashion.
- In light of the new evolutions, like tumor testing and targeted therapies, identify any gaps that may exist. Make sure pathologists and surgical oncologists, for example, can help identify high-risk members of a family. Examine the evolution to ensure that there are no gaps.
- Examine the opportunity to give patient-recorded outcomes to research to advance awareness and knowledge.
- There is a need for peer support while on clinical trials. Consider an online community companion to the trial for support.
- Perhaps categorize the work as what's new, since the last meeting given with the evolution of science, as well as what are the remaining major gaps.
- Under survivorship, consider the sexual health and menopause pieces separately. It is actually a cancer diagnosis treatment issue and not a survivorship issue. A woman of any age receiving the therapies may be put into a temporary menopause and experience mood changes, vaginal changes, etc. The University of Michigan has a robust prostate program that includes a two-hour

workshop that occurs before the men have surgery and it informs them of all the possible side effects and things to expect. The men are also automatically enrolled with a sex therapist in their follow-up. Is this level of information being given to women regarding their cancer treatment? Are the women being reached out to during treatment as well? Is there any referral base for any services that need to occur after the cancer treatment?

- Things that land in the bucket of survivorship are across the continuum of care.

After much discussion, it was decided that survivorship should be tackled by identifying the high-priority areas. Due to the many issues to address with survivorship, Dr. Fairley asked the group to identify just two areas to work on at this time, with the understanding that others will be addressed in the near future. The two highest priority areas were sexual health and mental/behavioral health. There was a unanimous vote (11 voting members) to sunset the current Survivorship Workgroup and create a Sexual Health Workgroup. There was also a unanimous vote to create a Mental/Behavioral Health Workgroup (11 voting members).

The following list of issues and concerns regarding sexual health was created to be examined by the Sexual Health Workgroup:

Sexual Health

- 10-year scope – literature review – BCYW
 - What's known?
 - Where are the gaps?
 - From a YW perspective
 - How providers are addressing problem
- How many YW have issues?
 - Provide overview on how YWBC affected - current
 - Resources
 - Gaps

It was universally voted (11 voting members) the charge of the Sexual Health Workgroup be to provide an overview of the current issues in sexual health, including resources, gaps, and evidence-based interventions for young women facing breast cancer. Individuals identified to be a part of this group are Dr. Lisa Chism, Ms. Anna Crollman, Ms. Ellyn Davidson, and Dr. Myriene Jeudy, with Dr. Chism and Ms. Davidson serving as co-chairs.

It was also decided unanimously the charge of the Mental/Behavioral Health Workgroup be to provide an overview of the current issues in mental/behavioral health, including resources, gaps, and evidence-based interventions for young women facing breast cancer. The chairs are Dr. Mylin Torres and Ms. Michele Maria Cerullo. Members include Ms. Carletta Cunningham, Ms. Jean Rowe, Dr. Marisa Weiss, Ms. Ricki Fairley, and Ms. Shonta Chambers.

Dr. Lin felt the Provider Workgroup's charge should stand as-is with the caveat that the group will deliberate on the provider-related issues that were discussed during the Hot Topic discussion from Day 1 of the meeting. These include accessibility, education for providers, and health care provider testing guidelines. Dr. Lin and Ms. Lindsay Avner will continue to serve as the co-chairs. The co-chairs will review previous notes and the work that has been completed. Any impasses identified will be raised for deliberation. The ACBCYW was in total agreement. Members will include Ms. Rowe, Dr. Shubhada Dhage, and Ms. Sue Friedman.

It was voted by all 11 members of the Committee to sunset the General Risk Assessment and Management Workgroup for now and to create the Genetics and Genomics Workgroup. The charge is to provide an overview of the utilization of genetic and genomic testing including the interpretation of risk and outcomes for young women facing breast cancer. The chairs will be Dr. Dhage and Ms. Joyce Tannenbaum Turner. Ms. Susan Brown and Ms. Friedman will serve as members.

There are now a total of four workgroups: Sexual Health, Mental/Behavioral Health, Provider, and Genetics and Genomics. As part of their charge, each workgroup will report findings from their research, as well as a summary of ideas, proposals, and solutions to the ACBCYW. The Committee will discuss the findings for each workgroup and vote on the formal recommendations that are submitted to the Director of CDC and the Secretary of HHS. Chairs are responsible for scheduling and coordinating meetings. Dr. Fairley and Ms. Carolyn Headley can assist the groups in a limited capacity. Chairs should foster engagement and dialog among the workgroup members. Any individuals who were not able to stay for the full duration of the meeting will be afforded the opportunity to join the workgroups.

Dr. Fairley and other CDC staff will keep track of the progress of the groups. Workgroups can request help and coordinate contact with subject matter experts within and outside of CDC. Since the workgroups are ad hoc, it is permissible to recruit members who are not a part of the committee as long as the ACBCYW members in the workgroup vote and are in charge of the facilitation of the group. CDC needs to be informed of the additional invited members.

The next conference will occur during or around February 2020, and will more than likely be a teleconference, but should an in-person meeting be warranted, it will be considered as well. In light of the upcoming meeting, workgroups should plan a six-month timeline for their work.

PUBLIC COMMENT

Dr. Gwendolyn Dean is a pediatrician. She would like to volunteer for the Provider Workgroup and offer a pediatric perspective. Menarche can occur at younger ages due to the endocrine disrupters in the environment. This increases the risk for breast cancer due to the length of time of estrogen influence. She can be contacted at gtdeanmd@gmail.com or 404-307-9575.

SUMMARY AND CLOSING

All slides presented, with the exception of Dr. Trogdon (presentation currently embargoed) will be uploaded to CDC' ACBCYW webpage. The workgroup thanked Dr. Fairley and Ms. Headley for their hard work in facilitating and working logistics. Dr. Fairley and Ms. Silber thanked the ACBCYW for its tireless drive and enthusiasm to bring changes and improvements for this population of women.

With no further comments, the meeting was adjourned at 11:43 a.m.

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

10.26.2019

Date

/Elana Silber/

Elana Silber, MBA, Chair
Advisory Committee on Breast Cancer in
Young Women



Centers for Disease Control and Prevention

ADVISORY COMMITTEE on **BREAST CANCER** in YOUNG WOMEN



Attachment 1: Published Meeting 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).

Monday, August 19, 2019

8:30 – 9:00 A.M.	Opening: ACBCYW Roll Call <i>Temeika Fairley, PhD</i> Designated Federal Officer, DCPC, CDC
9:00 – 9:15 A.M.	Welcome and DCPC Overview <i>Lisa Richardson, MD</i> Director, DCPC, CDC
9:15 – 9:40 A.M.	Introduction of ACBCYW Members <i>ACBCYW Committee Members</i>
9:40 – 10:10 A.M.	Introduction and Remarks <i>Elana Silber, MBA</i> Sharsheret ACBCYW Committee Chair
10:10 – 10:25 A.M.	Break
10:25 – 11:25 A.M.	Overview and History: Breast Cancer in Young Women 10 Years Later <i>Temeika Fairley, PhD</i> Designated Federal Officer, DCPC, CDC
11:25 A.M. – NOON	Updates from the Field

	<p><i>Justin Trogdon, PhD</i> Associate Professor, Health Policy and Management UNC Gillings School of Global Public Health</p>
NOON – 1:30 P.M.	Lunch
1:30 P.M. – 2:30 P.M.	<p>Updates from CDC</p> <p>Bring Your Brave Campaign Formative Research <i>Natasha Buchanan Lunsford, PhD</i> Behavioral Scientist, DCPC, CDC</p> <p>Bring Your Brave Campaign Updates and Future <i>Ally Moehring</i> Health Communication Specialist, Katmai Inc.</p>
2:30 – 3:15 P.M.	<p>Direct-to-Consumer Testing and Early-Onset Breast Cancer <i>Sadie Hutson, PhD, RN</i> Professor and Assistant Dean of Graduate Programs The University of Tennessee, Knoxville</p>
3:15 – 3:30 P.M.	Break
3:30 – 4:30 P.M.	<p>ACBCYW Open Discussion <i>Elana Silber</i> Sharsheret ACBCYW Committee Chair</p>
4:30 – 4:45 P.M.	PUBLIC COMMENT
4:45 – 5:00 P.M.	<p>Summary and Next Steps <i>Elana Silber</i> Sharsheret ACBCYW Committee Chair</p>

Tuesday, August 20, 2019

8:00 – 8:15 A.M.	<p>Opening: Welcome and Roll Call <i>Temeika Fairley, Ph.D.</i> Designated Federal Officer, DCPC, CDC</p>
8:15 – 8:30 A.M.	<p>Review and Highlights <i>Elana Silber</i> Sharsheret ACBCYW Committee Chair</p>

8:30 – 9:30 A.M.	<p>Updates from the Field</p> <p><i>Arin Ahlum Hanson, MPH, CHES</i> Associate Director, Outreach and Partnerships Living Beyond Breast Cancer</p> <p><i>Julia O’Hara, MPH</i> Program Manager, Gynecology Practice American College of Obstetrics and Gynecology</p>
9:30 – 11:15 A.M.	<p>ACBCYW Open Discussion</p> <p><i>Elana Silber</i> <i>Sharsheret</i> <i>ACBCYW Committee Chair</i></p>
11:15 – 11:30 A.M.	<p>PUBLIC COMMENT</p>
11:30 A.M. – NOON	<p>Summary and Closing</p> <p><i>Elana Silber</i> <i>Sharsheret</i> <i>ACBCYW Committee Chair</i></p>



Centers for Disease Control and Prevention

ADVISORY COMMITTEE on
BREAST CANCER in **YOUNG WOMEN**



Attachment 2: Roster of the ACBCYW Membership

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