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







Virtual Meeting of the Advisory Committee on Breast Cancer in Young Women April 17, 2015

Record of the Proceedings

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

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

ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN April 17, 2015

Minutes of the Virtual 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 a virtual meeting of the Advisory Committee on Breast Cancer in Young Women (ACBCYW) on April 17, 2015.

ACBCYW 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 (BCYW), particularly those at heightened risk.

Information for the public to attend the ACBCYW virtual meeting via webinar or teleconference was published in the *Federal Register* in accordance with Federal Advisory Committee Act regulations. All sessions of the meeting were open to the public (*Attachment 3: Participants' Directory*).

Opening Session

Jameka Blackmon, MBA, CMP

Public Health Advisor, Division of Cancer Prevention and Control Centers for Disease Control and Prevention ACBCYW Designated Federal Officer

Minutes of the Virtual Meeting

Advisory Committee on Breast Cancer in Young Women

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Ms. Blackmon conducted a roll call to determine the ACBCYW voting members, ex-officio members and liaison representatives who were attending the virtual meeting. She announced that the 14 voting members and ex-officio members in attendance constituted a quorum for ACBCYW to conduct its business on April 17, 2015 (Attachment 2: Roster of the ACBCYW Membership).

Ms. Blackmon called the proceedings to order at 1:13 p.m. EST and welcomed the participants to the ACBCYW virtual 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).

Ms. Blackmon asked the participants to join her in welcoming Dr. Lisa Richardson in her appointment as the new DCPC Director. She formally introduced Dr. Richardson by describing her leadership role as the DCPC Director and highlighting her notable accomplishments throughout her distinguished public health career at CDC since 1997.

Ann H. Partridge, MD, MPH Clinical Director, Breast Oncology Center Dana-Farber Cancer Institute ACBCYW Chair

Dr. Partridge also welcomed the participants to the ACBCYW virtual meeting. She was pleased to announce that the meeting would be devoted to the diligent efforts of the workgroups over the past two years in formulating updated recommendations for CDC's consideration and action. The recommendations would be compiled in a letter to the HHS Secretary as ACBCYW's formal guidance.

Lisa Richardson, MD, MPH Director, Division of Cancer Prevention and Control Centers for Disease Control and Prevention

Dr. Richardson thanked the ACBCYW members for their continued commitment to provide CDC with sound advice and guidance on its BCYW portfolio. She particularly thanked the outgoing members for their valuable service and contributions to this effort over the past five years. As the new DCPC Director, Dr. Richardson confirmed that ACBCYW's updated recommendations would be thoroughly reviewed and considered for action.

Update by the Ad Hoc Provider Workgroup

Generosa Grana, MD, FACP

Director, Cooper Cancer Institute ACBCYW Member & Provider Workgroup Chair

Dr. Grana reminded ACBCYW of several key points before reviewing the workgroup's draft recommendations. The workgroup was charged with developing guidance to assist healthcare providers (HCPs) in improving care and services for young women at risk for and diagnosed with breast cancer. The workgroup conducted three major activities to develop its first set of recommendations.

- Expanded the initial target audience of "providers" to include more specialties
- Explored strategies to better reach HCPs, such as targeted educational materials
- Reviewed the existing body of research on reaching HCPs with educational messages

The workgroup's updated recommendations focus on groups that have developed programs to reach different types of HCPs. Because many of these groups are challenged by systematically collecting data to build an evidence base, funding opportunities should be identified to evaluate and scale-up these activities at the national level. The workgroup's recommendations also emphasize the critical need for additional research in this area.

PROVIDER WORKGROUP RECOMMENDATIONS

- 1. In order to improve outcomes for young women at increased risk for breast cancer and those living with or surviving from the disease, continued attention is needed to ensure that healthcare providers can play a major role in partnering with at-risk women to address their needs and elicit their preferences.
- 2. Formative research is needed to assess the needs of various constituents in the provider network and also to identify effective strategies that allow targeting of high-risk groups. To the extent that best practices can be identified, these should be widely disseminated and their impact evaluated.
- 3. Several national programs, ranging from academically- to advocacy-based and many with CDC funding, are in various stages of dissemination and evaluation across the country. Each of these programs is focusing on innovative approaches to reach healthcare providers. Evaluation and expansion of these programs should be fostered along with strategies to bring providers together with at-risk women to help drive toward evidence-based, values-informed decisions

PROVIDER WORKGROUP RECOMMENDATIONS

- 4. Advances in healthcare and electronic medical record (EMR) systems that can both reach women and providers need to be developed and evaluated. The Provider Workgroup is ideally suited to focus on this area in the next iteration of ACBCYW.
- 5. The target audience of healthcare providers should include the following groups:
 - Primary care physicians (e.g., specialties in internal medicine, family medicine and obstetrics/ gynecology)
 - Trainees
 - Practicing providers
 - Nurse practitioners/physician assistants
 - Naturopaths
 - Insurance providers
 - Professional societies
 - Healthcare plans
- 6. The following strategies should be considered to reach healthcare providers:
 - Organizational meetings
 - Licensing boards
 - Training programs (e.g., Bright Pink Training Program and the University of Southern California Radiation Oncology Residency Training Program)
 - Insurance providers
 - Health Plan Medical Directors (e.g., the Michigan model)
 - National partners (e.g., Aetna, United Health and Cigna)
 - Newsletters
 - E-mail blasts
 - o Conferences for providers
 - Social networks that connect patients with providers
 - Online education
 - EMR innovations at point-of-care
- 7. Further research is critical and remains to be conducted in the field of effective outreach to healthcare providers. Funding, the needs of various audiences, and successful strategies must be identified to conduct this research.
- 8. Further support should be considered for groups that currently are conducting activities in the field of healthcare provider outreach. It is imperative to identify these groups and explore platforms to foster their collaboration. Funding opportunities should be identified to support, evaluate and expand the activities of these groups. Examples include:
 - Academic/community partnerships (Dr. Michael Wilkes at the University of California-Davis, Moffitt Cancer Center, and University of Michigan)
 - Advocacy groups (Bright Pink and FORCE)
 - CDC and its grantees
 - Existing clinical initiatives (Planned Parenthood)
 - Patient advocacy groups and online support groups

Dr. Partridge asked ACBCYW to focus its feedback on the two major themes of the workgroup's recommendations: (1) additional research to better reach HCPs with important health messages for their young patient populations and (2) funding to support research and ongoing programs that focus on provider education and communication. She confirmed that ACBCYW would have another opportunity to review and comment on the revised recommendations before the letter to the HHS Secretary is finalized and sent.

ACBCYW INPUT ON THE PROVIDER WORKGROUP RECOMMENDATIONS		
Recommendation #	ACBCYW Comments	Proposed Revisions
5	Medical and nursing school curricula do not explicitly cover care to the BCYW population. The continuing education unit process is needed to reach practicing physicians and nurses who have been out of school for quite some time and no longer participate in curriculum-based training.	 Add "medical and nursing students" as an additional target audience. Provide examples of specific types of "trainees:" residents, fellows and nurse/nurse practitioner trainees. Highlight schools of health professions that integrate multiple disciplines to collectively create interprofessional learning opportunities.
6	Accrediting bodies for medical and nursing schools should be listed as additional groups to reach HCPs. These groups should be aware of ACBCYW's ongoing efforts to improve education and training of HCPs who provide care to young patients.	ACBCYW's letter to the HHS Secretary should be succinct and concise. The proposed revisions for recommendation 5 will cover this suggestion.
6	Examples of EMR innovations should be described.	Include the Patient-Centered Clinical Research Network (PCORnet) as an example of an EMR innovation. PCORnet is being built as a nationally distributed research network that will link 70 million Americans to their EMRs. Due to its design, PCORnet will be able to target messages directly to a broad and diverse group of HCPs,

ACBCYW INPUT ON THE PROVIDER WORKGROUP RECOMMENDATIONS		
Recommendation #	ACBCYW Comments	Proposed Revisions
7	The recommendation underscores the need for research and funding to better reach HCPs, but a clearer explanation and additional details are needed.	including those with young highrisk patients who could benefit from genetic services. CDC is a PCORnet partner. Include new clarifying language: Funding is needed to continue research and evaluation on the efficacy of existing programs in reaching physicians, nurses and allied health professionals. For example, Bright Pink and Planned Parenthood have not yet collected impact and/or outcome data because evaluations of their programs are underway. Conclusions cannot be reached at this time on the success of these programs in changing provider knowledge and practice. Additional research also is needed to develop and define indicators to consistently measure effectiveness and

Update by the Ad Hoc High Risk Workgroup

Rochelle L. Shoretz, JD

Executive Director and Founder, Sharsheret ACBCYW Member & High Risk Workgroup Chair

Ann H. Partridge, MD, MPH
Clinical Director, Breast Oncology Center
Dana-Farber Cancer Institute
ACBCYW Chair

Ms. Shoretz and Dr. Partridge reviewed the workgroup's draft recommendations to guide ACBCYW's discussion.

HIGH RISK WORKGROUP RECOMMENDATIONS

- 1. ACBCYW should provide CDC with recommendations to advance the *Know:BRCA* social media initiative:
 - Leverage media attention in light of Breast Cancer Awareness Month and Ovarian Cancer Awareness Month.
 - Develop talking points to assist ACBCYW members who are contacted by the media in the upcoming months as the *Know:BRCA* Campaign continues to be implemented.
- 2. ACBCYW should take the following actions:
 - Clearly define, communicate and distinguish between "high risk" versus "general population risk"
 - Modify the High Risk Workgroup charge to have a stronger focus on general population risk
 - Engage in a more in-depth discussion on the *Know:BRCA* Campaign

ACBCYW noted that recommendation 2 appears to have integrated young women at the highest risk for breast cancer mortality and those at average risk. Several members expressed concern with this change because ACBCYW spent a considerable amount of time on clearly defining young women at higher than average risk and reaching this population through culturally-appropriate materials and other specialized resources. The workgroup's stronger focus on general population risk does not adequately address the needs of young women at higher than average risk.

ACBCYW also pointed out that high-risk young women increasingly are unable to access preventive services in accordance with National Comprehensive Cancer Network (NCCN) guidelines. The U.S. Preventive Services Task Force has not yet approved a Grade A or B recommendation for breast cancer prevention and screening services for women who already are designated as "high risk."

Dr. Partridge confirmed that ACBCYW would revisit these concerns after the update by the General Population Risk Workgroup.

Update by the Ad Hoc General Population Risk Workgroup

Lisa A. Newman, MD, MPH, FACS

Professor of Surgery and Director University of Michigan Health Systems ACBCYW Member & General Population Risk Workgroup Chair

Dr. Newman reminded ACBCYW of several key points before reviewing the workgroup's draft recommendations. The workgroup's initial activity in fulfilling its charge was to clearly define the general population of young women in the United States 20-45 years of age with no specific risk factors (e.g., no known hereditary susceptibility of breast cancer and no prior history of radiation).

The workgroup conducted a comprehensive literature review to determine the size of the target audience, identify changes in the general population of young women over time, and describe trends in the breast cancer burden among young women over the past few decades. The workgroup compiled key data from its review of recent studies to formulate messages for the general population of young women.

- The general population of young women in the United States 20-45 years of age has grown by ≈10 million persons from 1980 to 2010.
- Population-based incidence rates of breast cancer in the general population of young women have been relatively flat over the past few decades and are substantially lower than those for women >45 years of age. However, absolute numbers of young breast cancer patients have increased due to the larger size of the general population of young women.
- Population-based incidence rates of breast cancer are slightly higher among young African American women compared to young white women.
- Population-based incidence rates of triple-negative breast cancer are notably higher among young African American women compared to young women in other racial/ethnic groups.
- Breast cancer survival rates among all young women have been improving over time, but are lower in young African American women.
- Population-based incidence rates are continuing to increase among young women diagnosed with stage IV metastatic disease.

Dr. Newman reiterated that the workgroup had numerous discussions with its members and the full ACBCYW membership on whether to recommend a specific age at which to initiate mammography screening for young women <45 years of age. Based on these discussions, the workgroup's final decision was that ACBCYW should not make a recommendation.

GENERAL POPULATION RISK WORKGROUP RECOMMENDATIONS

Background

In the course of reviewing output from the High Risk Workgroup, it became apparent that a separate but aligned set of recommendations were needed regarding messages that should be promoted among the general population of young women in the United States. This realization led to the establishment of the General Population Workgroup.

These recommendations should be considered based on the efforts of the General Population Workgroup and ACBCYW as a whole. The recommendations are aimed at improving the care and outcomes of women in the United States 20-45 years of age with respect to breast cancer detection and diagnosis.

- Promote balanced messages to young women regarding their likelihood of being diagnosed with breast cancer Breast cancer is the most common malignancy diagnosed among women in the United States. Therefore, breast health awareness is important for women of ALL ages.Know:BRCA is a useful website for assessing individual breast cancer risk. This initiative should be promoted among women of all ages.
 - Women should be aware of genetic counseling services.
 - Breast cancer is relatively uncommon among the general population of women younger than 45 years of age in the United States. However, it is slightly less uncommon among African American women younger than 45 years of age compared to White American, Hispanic-Latina American and Asian American women.
 - ACBCYW recommends that CDC generate graphics appropriate for a lay audience to enhance the effectiveness of messages regarding age- and race-specific breast cancer risk.
- 2. Promote awareness of the fact that although breast cancer is uncommon in the general population of American women younger than 45 years of age, it can occur and the signs may be subtle.
 - Young women should therefore be aware of clinically-significant danger signs of breast cancer (e.g., bloody nipple discharge, new lumps, patches of nipple-areolar skin that appear scaly/ eczematoid, a new, persistent rash, or inflamed breast skin).
 - Young women undergoing mammography screening should know that mammograms have an increased false-negative rate for women younger than 50 years of age. Regardless of their most recent mammogram result, these women should seek medical attention if a danger sign appears.
- 3. Promote the importance of young women understanding their individual risk and whether their profile suggests a breast cancer risk that is higher than that of the general population of young women. Risk factors for young women outside of the general population include:
 - Family history of cancer and ancestral backgroundAshkenazi and African heritage

GENERAL POPULATION RISK WORKGROUP RECOMMENDATIONS

- Prior biopsy results that may have indicated increased risk (e.g., atypia and lobular carcinoma *in situ*)
- Prior chest wall radiation exposure that increases riskMammographically-defined extent of breast density
- 4. Promote awareness of the fact that young women can adopt several lifestyle practices and habits with effectiveness in reducing their future risk of breast cancer.
 - <u>Breastfeeding</u>. Any amount of breastfeeding is beneficial. The best level of protection comes from breastfeeding 12 months or more across one or more pregnancies.
 - Reduce alcohol intake. Drinking alcohol increases the risk of breast cancer. The risk increases as the amount of alcohol consumed increases.
 - Regular exercise. Exercising four or more hours per week may lower the risk of breast cancer, especially for women at a normal or low body weight.
 - These lifestyle messages should be promoted along with specific information regarding target body weight and body mass index.
- 5. Provide resources and promote research in the following areas that are poorly understood and/or under-funded with regard to breast cancer risk in young women:
 - Impact of poverty/socioeconomic factors on breast cancer risk
 - Breast cancer risk among lesbian, bisexual, and transgender individualsAccess to risk counseling servicesImproved and more efficient methods of detecting breast cancer and reducing its mortality among young women
 - Primary and secondary prevention strategies

Dr. Partridge hoped the workgroup's update addressed ACBCYW's concerns regarding the integration of recommendations and messages for the general population of young women and high-risk young women. Most notably, the lifestyle messages in recommendation 4 will be critical in promoting good breast health for young women at all levels of risk throughout their lifetime. However, Dr. Partridge encouraged ACBCYW to provide comments and propose revisions to address any outstanding concerns regarding women at higher than average risk of breast cancer.

ACBCYW INPUT ON THE GENERAL POPULATION RISK WORKGROUP RECOMMENDATIONS

Recommendation #	ACBCYW Comments	Proposed Revisions
1	The workgroup is to be commended for making a clear distinction between messages for healthy young women in the general population and highrisk women. The recommendation strikes an appropriate balance between promoting breast health awareness in healthy young women without instilling fear. However, the recommendation needs to be refined to address young women at higher than average risk of breast cancer who need culturally-appropriate educational interventions.	 Provide examples of graphics, such as those developed by Think Pink, to assist CDC in generating balanced and userfriendly messaging for the general population. Revise the language as follows: "ACBCYW recommends that CDC generate graphics appropriate for a lay audience to enhance the effectiveness of messages regarding age- and racespecific breast cancer risk. Young women at higher than average risk of breast cancer should be prioritized in this effort."
3	Other risk factors for young women outside of the general population should be highlighted.	Provide a link to NCCN's updated guidelines that describe non-BRCA gene mutations.
4	Several epidemiology experts have questioned whether sufficient data exist to inform the development of evidence-based recommendations on health behaviors that reduce breast cancer risk in the BCYW population. The proposed lifestyle practices have been examined in large, observational epidemiologic studies with select populations. The studies reported a decreased risk of lifetime breast cancer in their cohorts, but no data have been collected to show whether the proposed lifestyle practices prevented early onset breast cancer. The studies also did not measure or account for confounding factors.	 Include "smoking cessation" as an additional lifestyle practice due to its association with breast cancer rates. Add a footnote to emphasize that ACBCYW carefully weighed the pros and cons of formulating lifestyle messages with limited data: "The recommendations are based on the best available research."

ACBCYW INPUT ON THE GENERAL POPULATION RISK WORKGROUP RECOMMENDATIONS Recommendation # **ACBCYW Comments Proposed Revisions** 5 The proposed research agenda lists Include new research areas: five important areas that require Evidence-based interventions further study. However, other issues for young women at higher that need funding for new studies or than average risk of breast more robust research in the BCYW cancer. population should be described. Randomized clinical trials to determine the impact of lifestyle practices (e.g., breastfeeding, reduced alcohol intake and regular exercise) on reducing breast cancer risk in young women. Environmental risk factors at the system level that impact breast cancer risk in young women, such as the lack of fresh fruits and vegetables for young African American women in urban communities. • The role of social justice in the BCYW population, such as environmental exposures from toxic landfills in low-income communities that might impact breast cancer risk in young

Dr. Partridge requested ACBCYW's consensus on the draft recommendations presented by the workgroups. However, she confirmed that the revisions proposed by ACBCYW during the meeting would be captured in the letter to the HHS Secretary.

women.

Chair's call for a vote	A vote was taken for ACBCYW to formally adopt the 15 draft recommendations presented by the workgroups.
Outcome of vote	The 8 ACBCYW voting members unanimously passed the motion.
Next steps	Dr. Partridge will draft a letter to the HHS Secretary to highlight the workgroups' recommendations with ACBCYW's proposed revisions. The draft letter will be circulated to the

ACBCYW members for their review and comment before being finalized and sent to the HHS Secretary.

Dr. Partridge noted that ACBCYW's discussion on recommendations by the General Population Risk Workgroup resulted in several members expressing strong support to establish a new "Ad Hoc Social Justice Workgroup." ACBCYW made a number of comments to justify this new effort.

The Federal Interagency Breast Cancer and Environmental Research Coordinating Committee released a report in 2013 that documented a strong association between the environment and breast cancer risk. The new workgroup would use the interagency report and other existing studies as key resources in recommending research on issues related to social/environmental injustice, disparities and lack of access to care that particularly impact the BCYW population.

The new workgroup also would heavily rely on ACBCYW's liaison representatives who provide breast cancer care and services directly to young women in the field. The liaisons would play a critical role in describing social/environmental justice barriers in this population and proposing effective strategies for the research agenda.

Dr. Partridge announced that the High Risk Workgroup would be disbanded in the near future because high-risk young women are included in the recommendations and messages developed by the General Population Risk Workgroup. To ensure that ACBCYW is not overburdened with offline activities, the new Social Justice Workgroup would replace the High Risk Workgroup.

Chair's call for a vote	A vote was taken for ACBCYW to formally establish a new "Ad Hoc Social Justice Workgroup."
Outcome of vote	The 8 ACBCYW voting members unanimously passed the motion.
Next steps	 DCPC staff will develop the next meeting agenda with sufficient time for ACBCYW to engage in an in-depth discussion on the formal charge, membership and outcomes of the new workgroup. Preliminary charge: The workgroup will focus on social justice issues that have an impact on increased awareness, early detection and care of young women who are at risk for or develop breast cancer. Preliminary membership: Dr. Susan Kutner, an ACBCYW member, volunteered to chair the workgroup if her schedule permits or serve as a member.

Public Comment Session

Ms. Blackmon opened the floor for public comments; no participants responded.

Closing Session

Dr. Partridge asked the participants to join her in applauding Ms. Carolyn Headley, the ACBCYW Committee Management Specialist, and other DCPC staff for their continued efforts in planning, organizing and managing outstanding ACBCYW meetings. She also thanked Dr. Richardson for taking time from her busy schedule as the new DCPC Director to attend the ACBCYW virtual meeting.

Dr. Partridge thanked the ACBCYW members for their continued commitment to chair and serve on the workgroups and develop important guidance to improve the lives of young women with breast cancer. She reiterated that the draft letter to the HHS Secretary with ACBCYW's formal recommendations would be circulated to the members for review and comment before being finalized and sent. DCPC staff would poll the members regarding the date of the next ACBCYW meeting.

With no further discussion or business brought before ACBCYW, Ms. Blackmon adjourned the meeting at 2:58 p.m. EST on April 17, 2015.



Centers for Disease Control and Prevention

ADVISORY COMMITTEE on BREAST CANCER in YOUNG WOMEN

April 17, 2015 Virtual Meeting





Attachment 1 Published Meeting Agenda

MEETING OBJECTIVES:

Committee members are charged with advising the Secretary of the U.S. 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 (particularly among those at heightened risk).

Friday, April 17, 2015

1:00 P.M. – 1:15 P.M. Opening: Welcome, Roll Call, and Introductions

Jameka Blackmon, M.B.A., CMP
Designated Federal Officer, DCPC, CDC

Ann H. Partridge, M.D., M.P.H. Dana-Farber Cancer Institute ACBCYW Committee Chair

Lisa Richardson, M.D., M.P.H. Director, DCPC, CDC

1:15 P.M. –3:15 P.M. ACBCYW Workgroup Reports and Open Discussion

Ann H. Partridge, M.D., M.P.H. Dana-Farber Cancer Institute ACBCYW Committee Chair

Generosa Grana, M.D., F.A.C.P.
MD Anderson Cancer Center at Cooper
Ad Hoc Provider Workgroup

Lisa Newman, M.D., M.P.H., F.A.C.S. University of Michigan Health Systems Ad Hoc General Population Risk Workgroup

Rochelle Shoretz, J.D. Sharsheret Ad Hoc High Risk Workgroup

3:15 P.M. - 3:30 P.M. PUBLIC COMMENT

3:30 P.M. – 4:00 P.M. Summary and Closing

Ann H. Partridge, M.D., M.P.H. Dana-Farber Cancer Institute ACBCYW Committee Chair



ATTACHMENT 2 Roster of the ACBCYW Membership

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Centers for Disease Control and Prevention

ADVISORY COMMITTEE on BREAST CANCER in YOUNG WOMEN

April 17, 2015 Virtual Meeting





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Attachment 4 Glossary of Acronyms

ACBCYW	Advisory Committee on Breast Cancer in Young Women
BCYW	Breast Cancer in Young Women
CDC	Centers for Disease Control and Prevention
DCPC	Division of Cancer Prevention and Control
EMR	Electronic Medical Record
HCPs	Healthcare Providers
HHS	U.S. Department of Health and Human Services
NCCN	National Comprehensive Cancer Network
PCORnet	Patient-Centered Clinical Research Network