

Breast cancer in young women: research, program, and communications updates from CDC

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Centers for Disease Control and Prevention

Advisory Committee on Breast Cancer in Young Women Meeting

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Key Provisions of “EARLY ACT”

- Establish an evidence-based education campaign
 - Target women between ages 15 and 44
 - Target specific at-risk populations
 - African American women
 - Jewish women of Ashkenazi descent
 - Target messages to health care providers
- Research
- Survivor support
- Establish a Federal Advisory Committee on Breast Cancer in Young Women (ACBCYW)

2011 PROJECTS

Social Media Usage for Breast Cancer Awareness and Survivors

Social Media Usage for Breast Cancer Awareness and Survivors

Project Goal

- Provide research background, strategy, and recommendations for social media educational materials and interventions for young women ages 15-44 at risk for breast cancer and survivors.

Key Project Tasks:

1. Literature review and environmental scan
2. Formal partnership with an organization that has extensive expertise in engaging the target populations through social media
3. Expert panel to discuss social media as a tool for disseminating health information and psychosocial interventions and
4. Recommendations for disseminating results from the overall study to various programs and other stakeholders

Literature Scan

- Literature scan conducted November 2011–January 2012.
 - No studies evaluating use of social media to disseminate health information to young women at high risk for breast cancer.
 - 1 peer-reviewed study evaluating use of social media to support young women with breast cancer.
 - Literature focuses on social media habits of older women with breast cancer; minority populations underrepresented.
 - Broadened scan found several campaigns targeting young adults for public health purposes; studies could not be generalized.
- Formative research was needed.

POC: Temeika L. Fairley, PhD

Social Media Research Methods

- Research conducted February 2012–March 2012
- Social Media Monitoring
 - Computer program scanned social media conversations from February 2011 – February 2012, occurring across many platforms.
 - Collected conversations related to defined search terms.
 - Researchers quantitatively and qualitatively analyzed conversations.
 - Analysis of Social Media Strategies Used by Cancer Organizations
- Collected conversations and metrics on social media use of 8 organizations and their members.
- Analyzed conversations to identify “successful” organizational campaigns.

Next Steps and Tasks

Focus social media strategy development on three specific areas:

- Increase **awareness** among young women at high risk for breast cancer
- Provide **support** to young breast cancer survivors early in diagnosis, during treatment, and post-treatment
- Address prevention and treatment **myths** with scientific evidence

Revised Project Tasks:

1. Conduct additional social media monitoring research
2. Develop social media campaign strategies
3. Test strategies with target audience
4. Engage partner organization and experts in reviewing and revising campaign strategies

**ECONOMIC BURDEN OF BREAST CANCER
IN YOUNG WOMEN AGED 15-44 YEARS IN
THE UNITED STATES, 2000-2010**

Background and Purpose

- No studies quantify the economic burden of breast cancer in young women aged 15 to 44 years in the United States
- Estimate the economic burden of breast cancer among women aged 15 to 44 in the United States, by race/ethnicity
 - Comprehensive: direct, indirect and intangible costs
 - Stratified by race/ethnicity where possible

Study Progress

- Estimated intangible costs measured by quality of life (QoL) associated with breast cancer in young women
 - QoL decrement from breast cancer
 - Greater for women aged 18 to 44 than for women aged ≥ 45
 - Greater than for other cancers for women aged 18 to 44

Progress (Cont'd)

- Two abstracts accepted for presentation at the International Society for Pharmacoeconomics and Outcomes Research 17th Annual International Meeting in Washington DC, June 2-6, 2012
 - Breast Cancer Mortality Rates by Geographic Region, Years of Potential Life Lost, and Value of Productivity Losses among Women Aged 20-49 Years—United States, 1970–2008 [**Accepted as a podium presentation**]
 - Preference-Based Estimates of the Health Utility Impacts of Breast Cancer in US Women Ages 18-44 [**Accepted as a poster presentation**]
- Manuscripts are in process

Expected Outcomes/Dissemination

- Mini-reports describing cost estimates for:
 - Direct medical costs
 - Indirect (productivity) costs
 - Intangible costs
- At least three manuscripts suitable for peer-review
- Simplified messages for major stakeholders

**IMPACT OF GENOMICS AND PERSONALIZED
MEDICINE ON THE COST-EFFECTIVENESS OF
PREVENTING AND SCREENING FOR BREAST
CANCER IN YOUNGER WOMEN**

Project Background:

- Current guidelines recommended regular screening for women aged 50 and older but about 20 percent of breast cancers are diagnosed in women under age 50.
- Women with certain genetic mutations tend to develop breast cancer at younger ages and the disease is often more aggressive.
- Only some of the women who are at risk of developing breast cancer are identified by genetic tests currently available (BRCA1 and BRCA2).
- Technologies that are under development have the ability to look at multiple genetic variants and these tests when successfully implemented in clinical setting have the potential to transform medical practice along the continuum of cancer care.

POC: Florence Tangka, PhD

Purpose

- To compare the costs and benefits of enhanced genetic testing and personalized medicine as a potential mechanism for screening younger women increased risk of developing breast cancer.
- CDC is building an agent-based model to assess cost-effectiveness of breast cancer screening using novel technologies.

Project Methods

- Systematic literature search to identify new technologies for breast cancer screening has been completed
- Organizing technical expert panel for May
- Developing agent-based model

**DEVELOPING PSYCHOSOCIAL AND
REPRODUCTIVE HEALTH SUPPORT FOR YOUNG
BREAST CANCER SURVIVORS (YBCS) IN THE
UNITED STATES**

Project Overview

- The *Developing psychosocial and reproductive health support for young breast cancer survivors (YBCS) in the United States* project was launched in September 2010.
- Identify, strengthen, and promote real-world, evidence-based interventions providing **psychosocial** and **reproductive health** support to young breast cancer survivors (YBCS)
- Provides programmatic support to 2 national organizations that address the needs of and provide psychosocial and reproductive health-related intervention programs for young survivors
 - African American
 - Ashkenazi Jewish descent

Project Goals

- Identify core programmatic elements of organizations that provide psychosocial and reproductive health support to YBCS
- Identify the best methods to disseminate psychosocial and reproductive health support to YBCS
- Increase the use of evidence-based interventions
- Increase implementation of broader dissemination efforts

Project Tasks

- Assess the capacity of selected organizations to effectively develop, implement, and disseminate interventions providing psychosocial and reproductive health support for YBCS
- Identify and assess utility of existing programs supporting survivors
- Modify and implement programs (as needed)
- Prepare plan for a process and/or outcomes evaluation for modified/implemented SNI and Sharsheret programs
- Conduct evaluations to assess if modified programs for YBCS yield intended outcomes, are effective, and can be amplified and applied to other survivor audiences.

Project Updates: *Sharsheret*

- **Focus Groups**

- Our team received IRB approval for, and conducted focus groups with Jewish YBCS to test Sharsheret's Peer Support Network Program (PSN) and Genetics for Life Program (GFL).

- **Program Modifications**

- The PSN and GFL focus groups identified necessary modifications that Sharsheret is making to improve provision of psychosocial and reproductive health support to Jewish YBCS.

- **Program Evaluation**

- The Team has created logic models for the PSN and GFL. The logic models will serve as the foundation of the PSN and GFL outcome evaluation.
- We received OMB exemption to conduct the outcome evaluation of the PSN and GFL.

Focus Groups

- **Data Collection:**
 - In November 2011, Sharsheret conducted 4 focus groups with Jewish YBCS.
- **Purpose:**
 - To gain a deeper understanding of the health information needs and concerns of Jewish YBCS, and gather feedback on the PSN and GFL programs.
- **Analysis:**
 - Thematic notes-based analysis of qualitative focus group data.
 - Excel used to analyze pre discussion information sheet data.

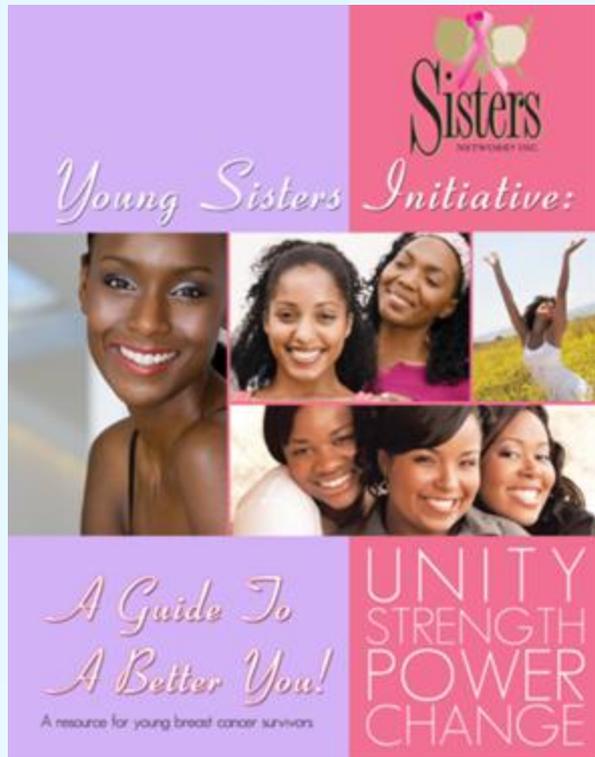
Focus Group Findings

- YBCS want to connect with a peer supporter immediately after diagnosis for guidance, validation, comfort, and hope.
- Information provided on what to expect physically and emotionally after diagnosis must be tailored to YBCS to avoid information overload.
- YBCS need information about the hereditary risk of breast cancer and related cancers, timely information about the impact of treatment on fertility, fertility preservation options, and the costs for these *before* treatment.
- Jewish YBCS need information about the impact of treatment on and how to cope with early menopause, body image, and issues with sexuality and intimacy.
- Jewish YBCS want psychosocial and reproductive health information from multiple sources (e.g., print, online, in person)., and an organization that is culturally relevant to Jewish women.

Program Modifications (to PSN and GFL)

- Expanded outreach efforts by placing organizational materials in locations that attract younger women.
- The PSN and GFL programs and resources will be delivered through multiple channels, including by phone and online.
 - The Sharsheret Web site will incorporate live chat technology and include online intake forms.
- Teleconferences will be offered to PSN and GFL participants on the financial and insurance concerns of YBCS and managing symptoms of early onset menopause.
- The GFL will offer women family conference calls to provide reproductive health support.
- At first contact, single women will be directed to the online transcript of Sharsheret's teleconference "Dating and Disclosure"

Project Update: *Sisters Network, Inc.*



Young Sisters Initiative (YSI): A Guide to a Better You goal:

- Genetic testing for breast cancer
- Types of breast cancer
- Treatment for breast cancer
- Coping with emotional issues related to cancer diagnosis and treatment
- Sexual health and fertility
- Guidance on communicating with health care providers about these issues.



Young Sisters Initiative: A Guide to a Better You!

Unity. Strength. Power. Change

Power



About the Young Sisters Initiative Program

Welcome and thank you for visiting the online Young Sisters Initiative (YSI) Program. The online YSI Program is designed to provide African American young breast cancer survivors (YBCS) with easy-to-read, culturally-tailored information and resources on genetic testing for breast cancer; types of breast cancer; treatment for breast cancer; coping with emotional issues that may arise as a result of cancer diagnosis and treatment; sexual and reproductive health; and guidance about how to best communicate with health care providers about these issues.

The YSI Program was developed by Sisters Network Inc. and the Centers for Disease Control and Prevention (CDC) to share emotional wellness and reproductive health information and resources with African American YBCS.

Register

OR

Log in



Young Sisters Initiative: A Guide to a Better You!

Pre YSI Website Use Demographic Screener

In order to access the YSI Program Website, please answer all of the following questions and click the "Submit" button below. Answering these questions should take no more than 5 minutes of your time. Your answers to these questions will not be shared with anyone other than members of the YSI Program Evaluation Team. Thank you for your interest in the YSI Program Website.

1. What is your current age?

2. Are you Hispanic or Latina?

 Yes No

3. Which one of these groups best represents your race?

 Black or African American White American Indian, Alaska Native Asian Native Hawaiian or other Pacific Islander

4. Were you diagnosed with breast cancer on or before your 45th birthday?

 Yes No

Please complete all fields.



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Video Placeholder

Welcome to the Young Sister's Initiative: A Guide to a Better You! program website. This website is an evidence-based, culturally-tailored, online program designed to provide African American, young breast cancer survivors (women diagnosed at 45 years of age or younger) with important psychosocial and reproductive health information and support. The online program provides users with information on issues including how to cope with having cancer as a young woman, dealing with fears of recurrence, concerns about fertility and sexual dysfunction, ways to cope with the side effects of breast cancer treatment, and strategies for communicating with health care providers about cancer related health concerns.

Did you know that the rate of breast cancer among women under 45 is higher for African American women than for any other racial group? Watch this short video for more important information about breast cancer and how this site can help you as an young breast cancer survivor.



Newly Diagnosed



In Treatment



Post Treatment



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Unity



YSI Program Workbook

Section	Summary
Introduction	Introduction This introductory section describes the purpose and goals of the YSI: A Guide to a Better You workbook. This section also provides guidance on how to use the workbook to suit your personal needs.
Section 1: Breast Cancer, Treatment, and Aftercare	Section 1: Breast Cancer, Treatment, and Aftercare Breast Cancer, Treatment, and Aftercare addresses the risk factors of breast cancer in young African American women. This section details the various types of breast cancer and treatment options. This section also lists options for care after completing active breast cancer treatment.
Section 2: Breast Cancer Risk and Your Family	Section 2: Breast Cancer Risk and Your Family Breast Cancer Risk and Your Family provides updated information regarding family history of breast cancer and your risks for inheriting genes that increase your risk of breast cancer. This section describes the preventive measures you can take if you discover that you have a family history of cancer and/or you have an inherited breast cancer gene mutation. It also explains genetic counseling and testing. Lastly, the section addresses how you can increase awareness of cancer in your family and community.
Section 3: Emotional Health and Wellness	Section 3: Emotional Health and Wellness The Emotional Health and Wellness section addresses the emotional impact of your cancer diagnosis and treatment. The section describes some of the feelings you may experience during diagnosis and treatment, listing the signs for depression, anxiety disorder, post-traumatic stress disorder, and other mental illnesses. This section also provides tips and suggestions on how to cope with the emotions related to your cancer diagnosis, treatment, and survivorship.
Section 4: Living With Breast Cancer: Family, Friends, and Workplace Issues	
Section 5: Premature Menopause and Breast Cancer	
Section 6: Health and Beauty	
Section 7: Breast Cancer, Sexuality, and Dating	
Section 8: Family, Pregnancy, and Motherhood After Breast Cancer	

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Section 1: Breast Cancer, Treatment, and Aftercare

One in Eight

Basic Information
about Breasts
and Breast Cancer

Stages of
Breast Cancer

How Breast
Cancer is Treated

Local Therapies

Systemic
Therapies

After Breast
Cancer Treatment
is Complete

Survivor Video

One in Eight

Every woman is at some risk of breast cancer. Overall, African American women are less likely than Caucasian women to get breast cancer. However, among the group of women who are diagnosed with breast cancer before age 45, a majority are African American. Scientists are not sure why this is. We know of some risk factors for breast cancer that affect most women; some of these are things you cannot change, like your current age, and some of them are things you can change, like getting exercise and maintaining a healthy weight.

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Basic Information about Breasts and Breast Cancer

Your breasts are made up of several different parts. The three main parts are:

- The glands that make milk for breastfeeding a baby
- The ducts that carry milk to the nipple
- The connective tissue (fat, skin, and small muscles and ligaments) that holds the breast together

Breast cancer happens when cells in your breasts grow and divide too quickly and crowd out normal cells. There are several different types of breast cancer.

- The most common type is ductal carcinoma, which develops in the lining of the tubes that take milk from milk glands to the nipple.

"The entire process for me has been filled with tears, laughter, and a lot of praying. Life looks completely different for me after this experience. You get to really see what really matters and what does not."

- Lisa Smith,
Breast Cancer
Survivor

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Next Steps

❑ **Evaluation**

- OMB approval
- Dissemination to target audience
- Analyze Data and Review findings
- Disseminate study findings

❑ **Study Completion in 2013-2014**

BODY TALK



Website and smartphone apps

Past milestones:

- December 2011 – Beta version of the website was released internally to CDC subject-matter experts for review and comment.
- September 2011 – Presented the website and concept to the ACBCYW members in Atlanta.
- August 2011 – User experience and concept testing completed. Testing included web pages and supporting documents.
- July 2011 – Prototype version of the website completed.



Website and smartphone apps

Current activities:

- April 2012 – Updated beta version of website currently being reviewed by members of the Advisory Committee for Breast Cancer in Young Women (ACBCYW).
- April 2012 – Both iPhone and Android apps scheduled to be completed by the end of the month.
- March 2012 – Development of updated beta version of the website completed.
- TBD – Rebrand the website and the smartphone apps with a name other than “BodyTalk.” Rebranding effort will include a new name, a new logo, and a new color scheme.

QUESTIONS AND DISCUSSION

Contact Information



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