



# Update from CDC: Public health's response to early onset breast cancer

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

Advisory Committee on  
Breast Cancer in Young Women  
August 23, 2022



# Background

- Breast cancer is the most commonly diagnosed cancer among women.
- About 10% 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 for breast cancer.
- Nearly 30% of women diagnosed with early breast cancer develop metastatic breast cancer (mBC) with an expected median survival between two to four years.



# The Legislation



The Breast Cancer **Education and Awareness Requires Learning Young Act (EARLY Act)**: the first piece of legislation related to breast cancer in young women, enacted in 2010. The EARLY 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

Establish a **program to provide support to young women living with breast cancer**

# Welcome and Thank You for Your Service

Advisory Committee on Breast Cancer in Young Women (ACBCYW)

- Chair: Cristina M. Checka, MD
- Heather Caro, MBA-HM, BSN
- Ashley Dedmon, MPH, CHES
- Jana Halaby
- Arin Ahlum Hanson, MPH
- Samantha Lynn Heller, PhD, MD, FSBI
- Michael Howard, MD
- Leigh Hurst
- Maryam B. Lustberg, MD, MPH
- Rebecca Muñoz, MPH, CHES®
- Heather Ochs-Balcom, PhD
- Melissa A. Peters, CPO, MSPO
- **Nicole B. Saphier, MD**
- Rebecca Seago-Coyle
- **Joyce Tannenbaum Turner MS, CGC**

# **Applied Public Health Research**

*Health Research to Guide Public Health Action*

# Different Approaches

- Additional questions to existing studies (Sister Study, Two Sister Study)
- Survey of women who had a medically-confirmed breast cancer diagnosis (through cancer registry data)
- Collaboration with one of CDC's Prevention Research Centers with expertise in modeling strategies

Journal of Occupational Rehabilitation (2021) 31:543–551  
https://doi.org/10.1007/s10926-020-09951-6

Check for updates

## Employment After Breast Cancer Diagnosis and Treatment Among Women in the Sister and the Two Sister Studies

Lucy A. Peipins<sup>1,5</sup> · Sabitha Dasari<sup>2</sup> · Juan L. Rodriguez<sup>1</sup> · Mary C. White<sup>1</sup> · M. Elizabeth Hodgson<sup>3</sup> · Dale P. Sandler<sup>4</sup>

Accepted: 25 November 2020 / Published online: 2 January 2021  
© This is a U.S. government work and not under copyright protection in the U.S.; foreign copyright protection may apply 2021

### Abstract

**Purpose** Women undergoing diagnosis and treatment for breast cancer may face challenges in employment. We investigated the impact of demographic, clinical, workplace, and psychosocial characteristics on loss of employment after a breast cancer diagnosis and treatment. We further describe changes in work status and work environment for cancer survivors who sustain employment. **Methods** We analyzed responses from a survey of breast cancer survivors from the Sister Study and the Two Sister Study cohorts who reported being employed at the time of their breast cancer diagnosis and who reported employment status (lost vs. sustained employment) at the time of survey administration. Multivariate logistic regression was used to identify the effects of lymphedema, neuropathy, problems with memory or attention, social support, health insurance, and sick leave on lost employment, adjusting for demographic characteristics, cancer stage, treatment, and general health. **Results** Of the 1675 respondents who reported being employed at the time of diagnosis, 83.5% reported being 'currently' employed at the time of the survey. Older age, peripheral neuropathy, lack of sick leave, late stage at diagnosis, a recurrence or a new cancer, problems with memory or attention, and poor general health were significantly associated with lost employment. **Conclusions** The long-term effects of breast cancer treatment and workplace provisions for leave and accommodation may have a substantial effect on women's ability to sustain employment. The findings from this study highlight challenges reported by cancer survivors that may inform clinical and occupational interventions to support survivors' return to work.

**Keywords** Breast cancer · Employment · Disability · Cancer survivors · Return to work

### Introduction

Each year, about a quarter million women in the United States are told they have breast cancer, and half are age 62 years and younger [1]. This means that for many women, breast cancer strikes during their peak earning years. Most breast cancers are diagnosed at early stages, and 5-year survival is nearly 90% [1]. A growing population at risk, [2] together with improvements in breast cancer treatment and survival, have resulted in an estimated 3.5 million women living with a breast cancer diagnosis (survivors) in the United States in 2016 [1]. That number is projected to climb to over 4.5 million by 2026 [3]. Some of these women will continue to work during diagnosis and treatment for breast cancer, and many may return to work once they complete treatment.

Employment benefits accrue to both society and to the individual. Society benefits economically from cancer survivors returning to work [4, 5]. For the cancer survivor, returning to work can mean a return to normalcy, an improved quality of life, financial security, and a sense of purpose or identity [6–9]. Despite the positive effects of work on women's well-being, cancer survivors face many challenges that may result in reduced or lost employment. Over the past 15 years, reviews of U.S. and European studies describe higher unemployment rates among cancer survivors than

HHS Public Access  
Author manuscript  
Eval Program Plann. Author manuscript; available in PMC 2021 October 22.

Published in final edited form as:  
Eval Program Plann. 2021 October; 88: 101967. doi:10.1016/j.evalproplan.2021.101967.

## Utility of linking survey and registry data to evaluate interventions and policies to address disparities in breast cancer survivorship among young women

Sujha Subramanian<sup>1\*</sup>, Madeleine Jones<sup>1</sup>, Florence K.L. Tangka<sup>2</sup>, Patrick Edwards<sup>3</sup>, Tim Flanigan<sup>4</sup>, Jenya Kaganova<sup>5</sup>, Kevin Smith<sup>6</sup>, Temeka Fairley<sup>7</sup>, Nikki A. Hawkins<sup>8</sup>, Juan L. Rodriguez<sup>9</sup>, Gery P. Guy Jr.<sup>9</sup>, Cheryl C. Thomas<sup>9</sup>

\*RTI International, 307 Waverly Oaks Road, Waltham, MA, 0245, USA  
<sup>1</sup>Centers for Disease Control and Prevention, 1600 Clifton Rd., Atlanta, GA, USA

### Abstract

**Purpose:** There is limited research linking data sources to evaluate the multifactorial impacts on the quality of treatment received and financial burden among young women with breast cancer. To address this gap and support future evaluation efforts, we examined the utility of combining patient survey and cancer registry data.

**Patient and Methods:** We administered a survey to women, aged 18–39 years, with breast cancer from four U.S. states. We conducted a systematic response-rate analysis and evaluated

\*Corresponding author at: RTI International, 307 Waverly Oaks Road, Waltham, MA, 0245, USA, subramanian@rti.org (S. Subramanian).  
CRediT authorship contribution statement  
Sujha Subramanian: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Data curation, Writing - original draft, Writing - review & editing, Visualization, Supervision, Project administration, Madeleine Jones: Validation, Formal analysis, Investigation, Resources, Data curation, Writing - original draft, Writing - review & editing, Visualization, Funding acquisition, Florence K.L. Tangka: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Data curation, Writing - review & editing, Supervision, Project administration, Patrick Edwards: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Data curation, Writing - original draft, Writing - review & editing, Visualization, Funding acquisition, Tim Flanigan: Software, Jenya Kaganova: Conceptualization, Methodology, Validation, Software, Formal analysis, Investigation, Resources, Data curation, Visualization, Kevin Smith: Validation, Formal analysis, Methodology, Temeka Fairley: Writing - review & editing, Project administration, Supervision, Funding acquisition, Supervision, Nikki A. Hawkins: Writing - review & editing, Project administration, Supervision, Funding acquisition, Supervision, Juan L. Rodriguez: Writing - review & editing, Project administration, Supervision, Funding acquisition, Supervision, Gery P. Guy: Writing - review & editing, Project administration, Supervision, Funding acquisition, Supervision, Cheryl C. Thomas: Writing - review & editing, Project administration, Supervision, Funding acquisition, Supervision.

**Ethical approval** "All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards."  
**Informed consent** Informed consent was obtained from all individual participants included in the study.  
**Statement on the welfare of animals** This article does not contain any studies with animals performed by any of the authors.  
**Declaration of Competing Interest** The authors have no conflicts to report.  
**Appendix A. Supplementary data** Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.evalproplan.2021.101967.

JNCI Cancer Spectrum (2021) 5(4): pkab063  
doi: 10.1093/jncics/pkab063  
First published online 13 July 2021  
Article

## Projecting the Prevalence and Costs of Metastatic Breast Cancer From 2015 through 2030

Anagha Gogate<sup>1</sup>, Ph.D, MHS,<sup>1</sup> Stephanie B. Wheeler, Ph.D, MPH,<sup>1,2,3</sup> Katherine E. Reeder-Hayes<sup>1</sup>, MD, MBA, MSc,<sup>2,4</sup> Donatus U. Ekwueme, Ph.D,<sup>5</sup> Temeka L. Fairley, Ph.D,<sup>5</sup> Sarah Drier<sup>6</sup>, MPH,<sup>7</sup> Justin G. Trogon<sup>1</sup>, Ph.D<sup>1,2,3,\*</sup>

<sup>1</sup>Department of Health Policy and Management, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA; <sup>2</sup>Lineberger Comprehensive Cancer Center, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA; <sup>3</sup>Center for Health Promotion and Disease Prevention, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA; <sup>4</sup>Division of Hematology/Oncology, Department of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA; and <sup>5</sup>Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, Atlanta, GA, USA  
\*Correspondence to: Justin G. Trogon, PhD, Department of Health Policy and Management, Gillings School of Global Public Health, 1101B McGarran-Greenberg Hall, CB #7411, University of North Carolina, Chapel Hill, NC 27599-7411, USA (e-mail: trogonj@email.unc.edu).

### Abstract

**Background:** This study projected the number of metastatic breast cancer (mBC) cases and costs (medical and productivity) attributable to mBC through 2030 among 3 age groups: younger (aged 18–44 years), midlife (aged 45–64 years), and older women (aged 65 years and older). **Methods:** We developed a stock/flow model in which women enter the mBC population at initial diagnosis (de novo stage IV) or through progression of an earlier-stage cancer. Women exit the mBC population through death. Input parameters by age and phase of treatment came from the US Census, Surveillance, Epidemiology, and End Results and peer-reviewed literature. **Results:** In 2030, we estimated there would be 246 194 prevalent cases of mBC, an increase of 54.8% from the 2015 estimate of 158 997. We estimated total costs (medical and productivity) of mBC across all age groups and phases of care were \$63.4 billion (95% sensitivity range = \$59.4–\$67.4 billion) in 2015 and would increase to \$152.4 billion (95% sensitivity range = \$111.6–\$220.4 billion) in 2030, an increase of 140%. Trends in estimated costs were higher for younger and midlife women than for older women. **Conclusions:** The cost of mBC could increase substantially in the coming decade, especially among younger and midlife women. Although accounting for trends in incidence, progression, and survival, our model did not attempt to forecast structural changes such as technological innovations in breast cancer treatment and health-care delivery reforms. These findings can motivate early detection activities, direct value-driven mBC treatment, and provide a useful baseline against which to measure the effect of prevention and treatment efforts.

Breast cancer is associated with a substantial economic cost to patients, payers, and society. In 2010, female breast cancer had the highest annual cost of any cancer site in the United States, estimated at \$16.5 billion (1). Metastatic breast cancer (mBC) is the most advanced form of breast cancer and is the costliest on a per-person basis (2). An earlier study estimated the total discounted societal cost attributable to mBC to be \$98.571 per patient-year, or \$12.2 billion in an incident cohort of 49 674 patients in 2007 (3). Estimated direct medical costs for this incident cohort were \$74.415 per patient-year. Early detection and effective treatment of early stages of disease are strategies to lower the total costs of mBC.

Prior studies have projected that cancer costs, broadly, and breast cancer costs, specifically, are expected to increase in the future (1,4). These trends are driven by such factors as the aging population, trends in incidence and survival within age groups, and increases in the cost of medical treatment. More recently, Mariotto et al. (5) projected the number of mBC cases in the United States through 2020. However, we are not aware of any studies that have projected medical and productivity costs for mBC cases further into the future. The objective of this study was to extend projections of the number of mBC cases from 2015 through 2030 and report projections of medical and productivity costs attributable to mBC among 3 different age groups: younger (aged 18–44 years), midlife (aged 45–64 years), and older women (aged 65 years and older). Although studies have reported medical care costs of breast cancer treatment for younger or older women (6–10), few have reported medical costs

# **Funding Organizations to Enhance Survivor Support**

# Purpose

The purpose of the cooperative agreement is to increase the availability of services and support for young breast cancer survivors (YBCS), metastatic breast cancer patients (mBC), and their families.



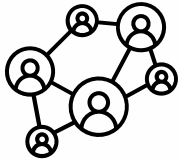
# Current Award Recipients

*CDC currently funds 8 organizations to provide support to young breast cancer survivors and metastatic breast cancer patients through a 5-year cooperative agreement (2019 – 2024).*

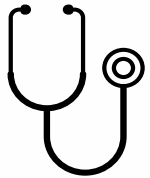


# Program Strategies

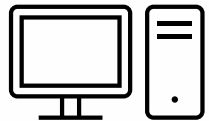
*To provide structured support services and resources that are designed to increase the survival and improve quality of life for YBCS and MBC.*



**Establish partner networks to facilitate policy, systems, and environmental change**



**Provide educational opportunities for health care providers**



**Develop innovative technological approaches to education**



**Engage patient navigators and community health workers**

## ***Bring Your Brave - Campaign Metrics & Progress***

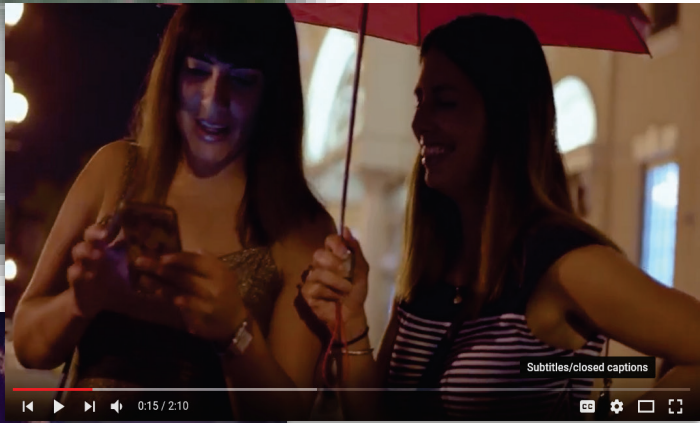
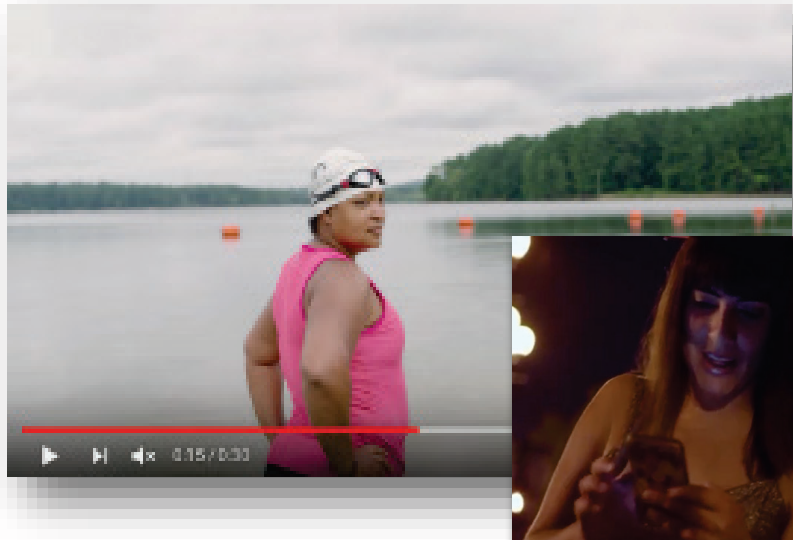
*CDC-developed tools and outreach programs for young women and health care providers*

# *Bring Your Brave* Campaign

- Public health campaign
- Targets young women *and* health care providers,
- Breast health & breast cancer education
- Launched in 2015



# Multimedia Storytelling...



# ...And Education...

## Digital Assets

**Thing To Know**

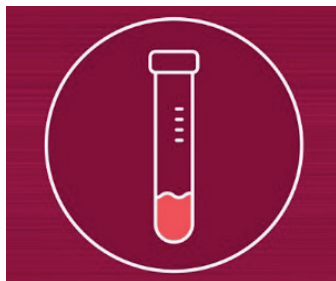
About 9% of new breast cancer cases in the US are found in women younger than 45.\*

\*But there are things you can do to manage and lower your risk.



Source: Centers for Disease Control and Prevention, 2020

## Direct-to-Consumer Genetic Testing Awareness



## Edutainment

Executive Producer: Sarah Watson  
Executive Producer: Joanna Coles  
Executive Producer: Ruben Fleischer  
Executive Producer: David Bernad  
Executive Producer: Victor Belli, Jr.  
Co-Executive Producer: Matthew McInnis  
Supervising Producer: Justin M. Lo  
Co-Producer: Wendy Straker Bauer

**the bold type**

"The Breast Issue"  
Episode #106

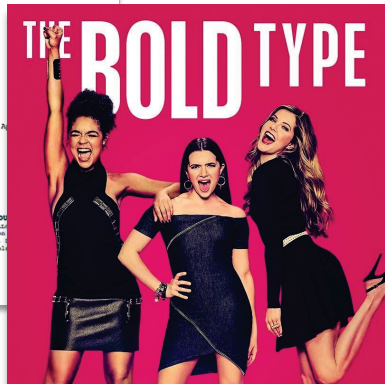
Written by  
Matthew McInnis

STUDIO/NETWORK DRAFT - A

Directed by: Jamie Travis

UNIVERSAL TELEVISION

© 2017 Universal Television LLC  
ALL RIGHTS RESERVED. NOT TO BE REPLICATED WITHOUT PERMISSION. THIS MATERIAL IS THE PROPERTY OF UNIVERSAL TELEVISION, LLC AND IS TO BE USED FOR THE USE BY THE PERSONNEL. THE SALE, COPYING, REPRODUCTION OR DISTRIBUTION OF THIS MATERIAL IN ANY FORM IS PROHIBITED. NO LIABILITY SHALL BE ASSUMED BY UNIVERSAL TELEVISION, LLC OR ANY OF ITS AFFILIATES FOR ANY DAMAGE OR LOSS OF PROFITS OR BUSINESS INTERRUPTIONS THAT MAY BE CAUSED BY THE USE OF THIS MATERIAL OR ANY INFORMATION CONTAINED HEREIN.



## "Ask the Expert" Videos



# **Bring Your Brave Health Care Provider Education**

*Supporting Medical Education Regarding Early Onset Breast Cancer*

# National Association of Chronic Disease Directors (NACDD)

- Informational video for health care providers about early onset breast cancer
- Link to additional resources and *Bring your Brave* website
- *Currently available on YouTube*

<https://www.youtube.com/watch?v=RlCs6vjcEIM>

[https://www.cdc.gov/cancer/breast/young\\_women/bring\\_yourbrave/health\\_care\\_provider\\_education/](https://www.cdc.gov/cancer/breast/young_women/bring_yourbrave/health_care_provider_education/)





## Medscape CME

In partnership with **Medscape**, the *Bring Your Brave* health care provider CME was launched and has resulted in:

- **29,007 learners**
- **11,654 test-takers**
- **10,050 CME certificates issued**
- **20,043.00 CME credits**
- Positive feedback from CME users

(\*Feb 2020 - Feb 2022)



# ACOG CME: Early Onset Breast Cancer Provider Education



Launched in 2020 in partnership with American College of Obstetricians and Gynecologists, as of June 2022 this CME has resulted in:

- 3,768 course registrations
- 1,867 course completions
- 13,069 CME/CEUs awarded

Out of individuals who completed the post-course survey (n=231) **99% said they would recommend the course to their colleagues.**

Out of individuals who completed the follow-up survey 3 months after completing the course (n=78) **84% reported implementing the information from the course in their practice.**

The promotional campaign has resulted in over

- 8 million impressions
- 40,000 unique page views ([acog.org/eobc](https://acog.org/eobc))

**1 IN 10  
WOMEN**

► Learn more.

**HER RISK IS INDIVIDUAL**

Course Learning Objectives:

- Identify: • Various risk factors for EOBC & how strong of a predictor each risk factor is
- Current guidelines and recommendations for EOBC & distinguish points of differentiation
- Existing data, including gaps, about breast density & EOBC risk

- Acquire effective risk assessment tools, communication tools & techniques to employ in patient interactions
- Interpret trends in data & identify ways to mitigate the impact of health disparities in EOBC

Learn more about the online course at [acog.org/eobc](https://acog.org/eobc)

**DON'T  
LUMP  
YOUR  
PATIENTS  
TOGETHER**

Help manage her risk for early onset breast cancer

**LEARN MORE**

Go to: **ACOG.org/EOBC**  
to learn more

**What's New and What's Next from *Bring Your Brave***

# Entertainment Education

NBC's hit medical drama, "New Amsterdam," (fall 2021) featured a storyline about breast cancer as part of the network's national Breast Cancer Awareness Month Campaign

- Women with dense breast tissue can be at higher risk for developing breast cancer
- Additional screening may be needed for women who a determined to have dense breast tissue in a mammogram



# Let's Talk: Sharing Info About Your Family Cancer Risk Module

Launched in November 2021, the **Let's Talk: Sharing Info About Your Family Cancer Risk** module allows users to practice talking with a family member about their hereditary breast and ovarian cancer risk and health decisions.



Learn how to talk about cancer risk that may run in your family. Practice bringing it up with a family member and helping them make good decisions about their health.

This project is being done through a cooperative agreement with the National Association of Chronic Disease Directors.

# *Let's Talk: Sharing Info About Your Family Cancer Risk Module*

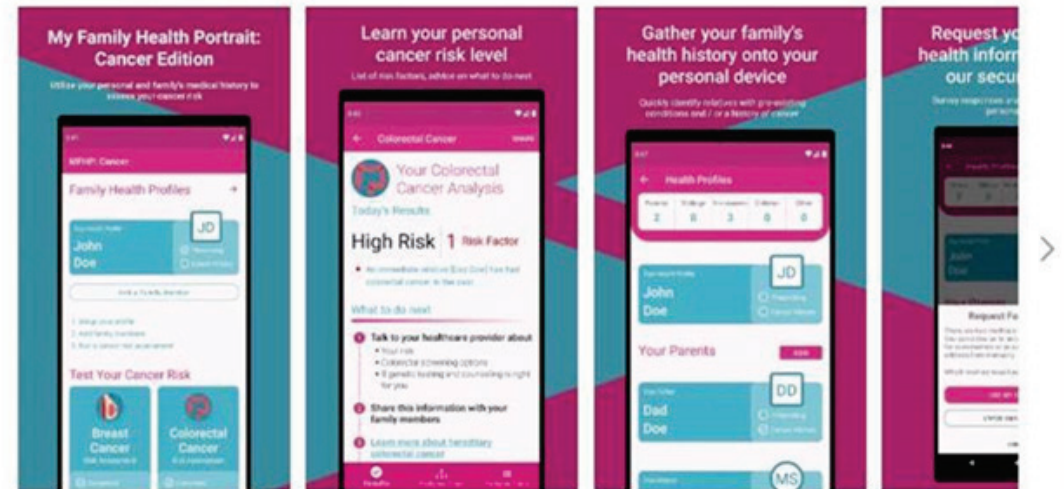
Accompanying the interactive tool are **authentic stories from women affected by hereditary breast and ovarian cancer** sharing how their family talks about these risks or how they plan to have these conversations with family, including their own children, in the future.



This project is being done through a cooperative agreement with the National Association of Chronic Disease Directors.

# My Family Health Portrait: Cancer (MFHP: Cancer)

- Mobile health application for persons at risk for hereditary cancer
- Helps users to collect and record their family's history of cancer and conduct basic hereditary cancer risk assessments (breast, ovarian, and colorectal)
- Provide visual hereditary cancer pedigree chart
- Supports patient and health care provider discussions about their family history of hereditary cancers



**IOS version coming soon!**

# My Family Health Portrait: Cancer (MFHP:Cancer)

## MFHP Cancer



### Be Prepared

Find out if you are at higher risk for developing cancer.

Skip



Next

## MFHP Cancer



### Be Thorough

Access your family's history of cancer

The more history you enter, the more accurate your results

You can still learn more about your risk even if you do not know your complete family history of cancer

Skip



Next

## MFHP Cancer



### Be Proactive

1. Create your profile (2 mins)
2. Add family members (5-20 mins)
3. Run risk assessments (5 mins)
4. View your results (2 mins)
5. Learn about potential next steps

Skip



Get Started

## MFHP Cancer



### Be Private

You control who sees your personal and private family history

You have the option to share these results with your healthcare provider

Skip



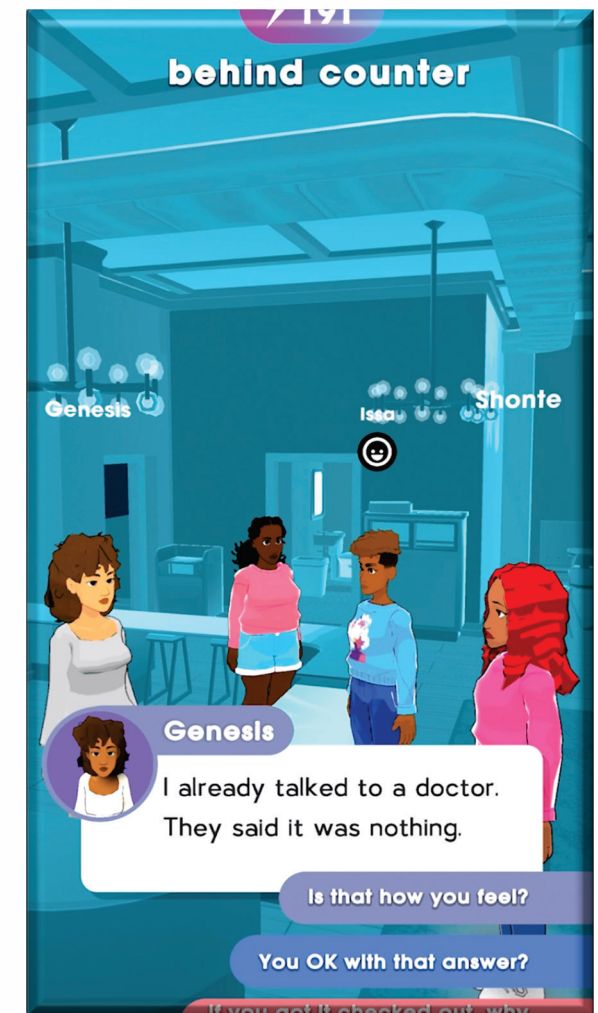
Next



# Mobile Game Narrative Integration

CDC is partnering with a women of color-led team to reach young Black women about breast cancer.

Glow Up Games' mobile game, *Insecure: The Come-Up Game* based on HBO's hit show, *Insecure*.



Images from *Insecure: The Come-Up Game*

# The Legislation



The Breast Cancer **Education and Awareness Requires Learning Young Act (EARLY Act)**: the first piece of legislation related to breast cancer in young women, enacted in 2010. The EARLY 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

Establish a **program to provide support to young women living with breast cancer**

# Thank you!

Go to the official federal source of cancer prevention information:  
[www.cdc.gov/cancer](http://www.cdc.gov/cancer)



Division of Cancer Prevention and Control  
Reliable. Trusted. Scientific.

*The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.*