United States Government Accountability Office

Report to Congressional Committees

October 2016

BREAST CANCER EDUCATION

HHS Has Implemented Initiatives Aimed at Young Women

GAO Highlights

Highlights of GAO-17-19, a report to congressional committees

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BREAST CANCER EDUCATION

HHS Has Implemented Initiatives Aimed at Young Women

Why GAO Did This Study

While most breast cancer is detected in older women, breast cancer also affects young women (defined as women under 45 years old). Researchers have found that young women affected by breast cancer tend to be diagnosed at a later stage, experience worse outcomes, and face unique issues in their treatment, such as effects on fertility. The EARLY Act requires HHS to provide breast cancer education and support specifically for young women. The 2014 reauthorization of the act included provisions that GAO identify HHS activities to provide breast cancer education, and assess whether such activities are duplicative of other federal breast cancer education efforts. This report addresses (1) HHS's efforts to provide or support breast cancer education for young women, and (2) whether these efforts for young women duplicate other federal breast cancer education efforts.

In conducting this work, GAO reviewed federal laws, federal internal control standards, GAO's Fragmentation, Duplication, and Overlap Guide, as well as HHS's documentation of EARLY Act efforts and spending; and interviewed officials at HHS agencies with roles implementing the act, including CDC, HRSA, and NIH. GAO also interviewed officials from seven research and advocacy groups who were selected based on the populations they represent, and searched 17 federal websites, which were selected based on GAO's research and referrals by breast cancer experts.

HHS provided technical comments on a draft of this report, which GAO incorporated as appropriate.

View GAO-17-19. For more information, contact Marcia Crosse at (202) 512-7114 or CrosseM@gao.gov.

What GAO Found

The Centers for Disease Control and Prevention (CDC), within the Department of Health and Human Services (HHS), has led federal efforts to respond to four areas specified in the Young Women's Breast Health Education and Awareness Requires Learning Young Act of 2009 (EARLY Act). CDC reported spending nearly $37 million between fiscal years 2010 to 2016 on the following efforts across the four areas specified in the act:

- Prevention research: CDC developed research in areas such as the economic implications of breast cancer, infertility, and survivorship, as well as participated in research conducted by the National Institutes of Health (NIH).
- Public education campaign: To educate women at risk of or living with breast cancer, including those with a breast cancer susceptibility gene (BRCA) mutation, CDC launched *Know*: *BRCA*—an interactive web resource that enables women to determine their potential breast cancer risk—in 2014, and *Bring Your Brave*—a web-based campaign—in 2015.

Centers for Disease Control and Prevention (CDC) Promotional Material for *Know: BRCA*

Source: CDC. | GAO-17-19

- Support grants: CDC awarded 14 grants to entities that increase education and awareness, and provide support programs for young women with breast cancer—particularly the target populations specified in the EARLY Act.
- Health professional education campaign: Efforts for this campaign are more recent and have focused on developing continuing education case studies for providers and provider components of *Know: BRCA* and *Bring Your Brave*. CDC officials are beginning to work with the Health Resources and Services Administration (HRSA) to reach providers.

GAO determined that HHS's targeted breast cancer education campaign for young women leverages existing resources, but does not duplicate other federal breast cancer education efforts, which are more general in nature. Additionally, a breast cancer expert noted that breast cancer education for young women is new and evolving, thus, further limiting the possibility that recent efforts are duplicative.

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Abbreviations

BRCA	breast cancer susceptibility gene
CDC	Centers for Disease Control and Prevention
EARLY Act	Young Women's Breast Health Education and Awareness Requires Learning Young Act of 2009
HHS	Department of Health and Human Services
HRSA	Health Resources and Services Administration
NCI	National Cancer Institute
NIH	National Institutes of Health

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October 20, 2016

The Honorable Lamar Alexander
Chairman
The Honorable Patty Murray
Ranking Member
Committee on Health, Education, Labor, and Pensions
United States Senate

The Honorable Fred Upton
Chairman
The Honorable Frank Pallone
Ranking Member
Committee on Energy and Commerce
House of Representatives

According to the American Cancer Society, about 1 in 8 women will develop breast cancer in their lifetimes, making breast cancer one of the most common cancers among women in the United States. While most breast cancer occurs in older women, about 11 percent of all new cases of breast cancer in the United States are found in young women, defined as women under 45 years of age. Researchers have found that young women tend to be diagnosed at a later stage with more aggressive breast cancer and experience worse outcomes, including lower survival rates, than older women. Young women also face unique issues in their treatment and recovery from cancer—such as effects on finances, fertility, and body image—that differ from issues older women face in managing the disease. Additionally, some young women are at a higher risk of developing breast cancer at an early age compared with other women their age, depending on multiple factors, such as cultural background, family history, and personal history of certain cancers.[1]

The Young Women's Breast Health Education and Awareness Requires Learning Young Act of 2009 (EARLY Act) requires the Department of

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[1] With respect to cultural background, the Centers for Disease Control and Prevention's (CDC) website indicates that women under 45 years old may have a higher risk of developing breast cancer if they have an Ashkenazi Jewish heritage, among other factors specified.

Health and Human Services (HHS) to provide breast cancer education and support specifically to young women.[2] In particular, the EARLY Act directs HHS to develop education campaigns for the public and health care providers, establish an advisory committee to assist in creating the campaigns, conduct prevention research activities, and provide support for young women diagnosed with breast cancer. In 2014, the EARLY Act was reauthorized through fiscal year 2019 and included a provision that we identify HHS activities that provide or support breast cancer education as described in the EARLY Act, and identify any activities that duplicate other federal breast cancer education efforts.[3] In this report, we

(1) identify efforts HHS has undertaken to provide or support breast cancer education for young women as required in the EARLY Act, and

(2) examine the extent to which these efforts duplicate other federal breast cancer education efforts for young women.

To identify efforts that HHS has undertaken in response to the EARLY Act, we reviewed relevant federal laws and HHS documentation, including materials associated with the Advisory Committee on Breast Cancer in Young Women, which the Centers for Disease Control and Prevention (CDC) established in 2010. We also reviewed documentation of spending information provided by CDC related to their efforts to respond to the act. Additionally, we interviewed HHS officials charged with EARLY Act implementation, including officials at the CDC, the Health Resources and Services Administration (HRSA), and the National Institutes of Health (NIH). We also interviewed officials from three other federal entities and seven research and advocacy organizations, which we selected based on

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[2] The EARLY Act was enacted as part of the Patient Protection and Affordable Care Act. Pub. L. No. 111-148, § 10413, 124 Stat. 119, 990-93 (2010) (codified, as amended, at 42 U.S.C. § 280m).

[3] EARLY Act Reauthorization of 2014, Pub. L. No. 113-265, 128 Stat. 2942 (2014).

their association with the advisory committee and the populations they represent.[4]

To examine the extent to which HHS's efforts developed under the EARLY Act duplicate other federal breast cancer efforts for young women, we reviewed federal internal control standards and GAO's Fragmentation, Duplication, and Overlap guide.[5] We also selected and searched 17 federal websites for content targeted specifically to breast cancer education for young women. We selected the 17 websites to include the agencies represented on the advisory committee, and based on referrals by breast cancer experts and our research of federal entities that relate to aspects of the EARLY Act—such as women's health, cultural diversity, prevention, screening, or research.[6] For each of the 17 federal websites, we used the Google Advance Search feature to identify potentially duplicative content related to breast cancer education for young women.[7] Using search terms such as "breast cancer," "young women," "women between," and "women under," these websites

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[4] These officials represented the following agencies, organizations, or institutions: Asian Women for Health; Bright Pink; Dana-Farber Cancer Institute; the Department of Defense's Congressionally Directed Medical Research Program; FORCE: Facing Our Risk of Cancer Empowered; HHS's Office on Women's Health; Sharsheret; Sister's Network, Inc.; and Young Survival Coalition.

[5] See GAO, *Standards for Internal Control in the Federal Government*, GAO-14-704G (Washington, D.C.: Sept. 10, 2014). Internal control is a process effected by an entity's oversight body, management, and other personnel that provides reasonable assurance that the objectives of an entity will be achieved. See also GAO, *Fragmentation, Duplication, and Overlap: An Evaluation and Management Guide*, GAO-15-49SP (Washington, D.C.: April 14, 2015).

[6] The 17 selected websites were from the following federal entities: Agency for Healthcare Research and Quality, CDC, Congressionally Directed Medical Research Program, Department of Defense, Department of Education, Department of Veterans Affairs, Food and Drug Administration, HHS's Office of Minority Health, HHS's Office of Disease Prevention and Health Promotion, HHS's Office on Women's Health, HRSA, Indian Health Service, Initiative on Asian Americans and Pacific Islanders, NIH, National Cancer Institute, National Institute of Environment Health Sciences, and National Human Genome Research Institute.

[7] The Google Advance Search feature can be found at https://www.google.com/advanced_search, accessed on August 29, 2016.

generated a list of over 400 results.[8] We examined these results to assess the extent to which identified content duplicated aspects of CDC's public education campaign.[9] Specifically, we reviewed this content against criteria, such as the targeted audience (all women, younger women, or older women); whether it pertained to breast cancer only or included information on other types of cancers; and whether it was a part of an education campaign, among other factors.[10] Based on this review, we determined whether the content was potentially duplicative (i.e., was targeted at young women, pertained only to breast cancer, and was part of an education campaign), not duplicative, or unrelated to CDC's targeted campaign. Multiple analysts reviewed the content independently to make this determination, which was verified by another analyst.

We conducted this performance audit from January 2016 to October 2016 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Background

According to the American Cancer Society, about 247,000 women will be newly diagnosed with breast cancer in 2016. It is estimated that 11 percent, or about 27,000, of these new cases will occur in young women, defined as women under 45 years of age. Breast cancer researchers

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[8] We identified over 400 search results on May 24, 2016, for further review. Our results reflect our review of web page content from May through August 2016, and do not reflect any subsequent changes that may have been made by the respective federal agencies.

[9] Within HHS, the EARLY Act specified roles and responsibilities for CDC, HRSA, and NIH in implementing breast cancer education and support activities. However, we limited our examination of potential duplication to CDC education campaign activities, because CDC and HRSA officials reported that they are just beginning efforts related to provider education and because NIH's role in the act is related to conducting prevention research to develop new screening tests and methods for the prevention and early detection of breast cancer in young women.

[10] In applying these criteria, we also considered the date of the webpage, excluding content posted prior to 2010, and whether the content was a reposting of CDC's campaign efforts under the EARLY Act. We did not consider a reposting of CDC's campaign materials on another federal website to be duplicative.

have indicated that while young women are a small portion of the population facing a breast cancer diagnosis, they have unique and complex issues in managing the disease. For example, young women with breast cancer may be concerned about parenting young children during treatment, body image, and the effect that treatment may have on future fertility and their professional lives. Additionally, some young women are at a higher risk for developing breast cancer at an early age due to certain factors, such as their family history or changes in certain genes called breast cancer susceptibility genes, or BRCA.[11] These genes—BRCA 1 and BRCA2—normally prevent cancer from developing. However, when there are changes or mutations on one or both of the BRCA genes, cells are more likely to divide rapidly, which can lead to cancer. Without treatment, women with a BRCA gene mutation are seven times more likely to develop breast cancer before age 70 compared with other women their age.

The EARLY Act directs HHS, including through CDC, HRSA, and NIH, to increase education and support for young women diagnosed with breast cancer by undertaking efforts in four specified areas: (1) prevention research, (2) a public education campaign, (3) support for young women diagnosed with breast cancer, and (4) a health professional education campaign. The act identifies the following key activities and often specifies responsible HHS agencies.

- <u>Prevention research:</u> CDC is to conduct breast cancer prevention research activities, including behavioral and survivorship studies, formative research to assist in developing educational messages, and testing social marketing strategies targeted at young women. In addition, NIH is required to conduct research to develop and validate new screening tests and methods for prevention and early detection of breast cancer in young women.
- <u>Public education campaign:</u> CDC is to conduct a national public education campaign to increase awareness for young women about

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[11] For example, women under age 45 may have a higher risk if they had a close relative who was diagnosed with breast or ovarian cancer when they were younger than 45; if they have changes in certain breast cancer genes (BRCA1 and BRCA2), or have close relatives with these changes; if they were treated with radiation therapy to the breast or chest during childhood or early adulthood; or if they are of an Ashkenazi Jewish heritage.

breast cancer, and to establish an advisory committee to assist in the creation and execution of this campaign.

- Support for young women diagnosed with breast cancer: HHS is to award grants to organizations and institutions to provide health information and assistance to young women diagnosed with breast cancer. The act specifies that in awarding such grants, priority is to be given to applicants that work specifically with young women diagnosed with breast cancer.
- Health professional education campaign: CDC, in consultation with HRSA and with the assistance of the advisory committee established by CDC, is to conduct an education campaign for physicians and other health care professionals. The purpose of this campaign is to increase awareness related to breast health, early diagnosis, treatment, and specific risk factors for certain women, as well as the provision of counseling about family cancer history and referrals for genetic testing, among other factors.

HHS Has Undertaken Several Breast Cancer Education Efforts in Response to the EARLY Act, Spending Nearly $37 Million since 2010

In leading HHS efforts to provide breast cancer education and support for young women across all four areas specified in the EARLY Act, officials reported that CDC was the only agency identified in the act to receive funding to do so. Accordingly, CDC reported spending nearly $37 million between fiscal years 2010 and 2016, most of which was for prevention research efforts and support grants to organizations that provide assistance to young women diagnosed with breast cancer.[12] (See fig. 1.)

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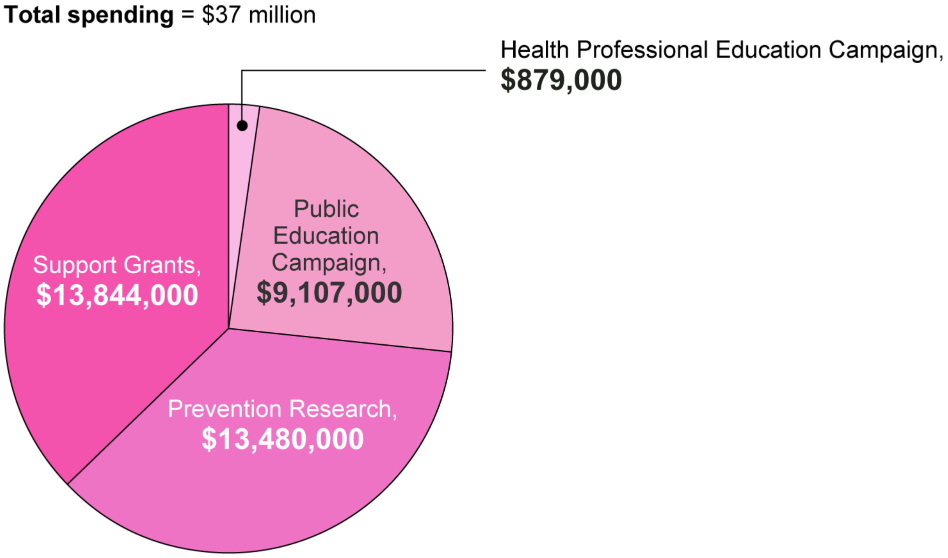
[12] According to CDC, the spending information they provided represents outlays for fiscal years 2010 through 2015, and obligations for fiscal year 2016.

Figure 1: Centers for Disease Control and Prevention (CDC) Reported Spending on EARLY Act Activities, Fiscal Years 2010 through 2016



Source: CDC. | GAO-17-19

Note: According to CDC, the spending information they provided for activities under the Young Women's Breast Health Education and Awareness Requires Learning Young Act of 2009 (EARLY Act) represents outlays for fiscal years 2010 through 2015, and obligations for fiscal year 2016.

Specifically, CDC reported spending EARLY Act funds on the following efforts in each of the four areas.

Prevention research

With reported spending of about $13.5 million since 2010, CDC initiated a number of prevention research activities related to developing messages for the targeted populations, survivorship, and the effect of a breast cancer diagnosis on young women, among other issues. As initial steps to learn about the needs of young women with breast cancer and to generate appropriate information to target to them, CDC commissioned a literature review, convened an expert panel, and participated in an ongoing NIH study examining breast cancer risk factors in women who have sisters with cancer. The literature review looked across media and research to identify what is known about breast cancer in young women, while the expert panel focused on identifying communication and research issues that might affect this population.[13] Additionally, CDC partnered with NIH to identify the needs of young women with breast cancer and evaluate how breast cancer affects screening and lifestyle behaviors in sisters of young women with breast cancer, as part of NIH's Sister Study.[14] CDC also initiated other research regarding specific issues that young women face in managing breast cancer, such as the economic implications of the disease, and the effect of treatment on fertility, which resulted in a number of publications. For example, one study found the need for more age-appropriate interventions to help reduce substantial health and economic burdens, improve survival, and reduce productivity costs associated with premature death.[15]

To augment ongoing research related to cancer genomics, CDC also awarded grants to state health departments in Colorado, Connecticut, Georgia, Michigan, Oregon, and Utah.[16] The grants allow states to develop or expand programs to assess the burden of hereditary cancer and the use of genetic counseling, genetic testing, and associated clinical services in the state; educate the public and providers about hereditary cancer; and improve access to and health insurance coverage of associated clinical services for people with a high risk of developing hereditary cancer. For example, Colorado is using its grant to improve the

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[13] The findings from the expert panel highlighted early detection strategies, including screening, risk assessment, and genetic counseling, as well as survivorship issues, follow-up care, fertility and reproductive health, and psychosocial care, and were subsequently published. See Buchanan, Natasha, et al., *Opportunities for public health communication, intervention, and future research on breast cancer in younger women*, Journal of Women's Health 22.4 (2013): 293-298, accessed August 15, 2016, http://online.liebertpub.com/doi/abs/10.1089/jwh.2012.4239.

[14] The Sister Study is conducted by NIH's National Institute of Environmental Health Sciences, and includes over 50,000 women across the country who are between the ages of 35-74, and who have a sister with breast cancer. CDC officials indicated that since there is no population data set specific to young women with breast cancer, they added questions to the questionnaires used in the study in order to collect information about this population of women.

[15] See Ekwueme, D and J. Trogdon, *The Economics of Breast Cancer in Younger Women in the US*, American Journal of Preventive Medicine, vol. 50, no. 2, 249-254 (2016).

[16] Cancer genomics is the study of changes or abnormalities in genetic material that drive the development of many types of cancer. Knowledge gained from cancer genomics work improves understanding of the biology of cancer, which can lead to new methods of diagnosing and treating the disease.

state's ability to measure awareness and utilization of cancer genetic services. Other state efforts related to these genomics grants include placing cancer genetic services and counselors in particular areas, especially counties with a high incidence of hereditary cancers, such as early-onset breast cancer.

The EARLY Act also specified a role for NIH in conducting prevention research, and NIH officials provided documentation on a significant body of ongoing National Cancer Institute (NCI) supported breast cancer research relating to early detection, screening, prevention, and genetics, including several studies focused on young women.[17] For example, one project is focused on the determinants of breast tissue composition in young women, while another is looking into the familial history and future of young women from families with a BRCA 1 or BRCA 2 mutation. Within these projects, NIH officials also highlighted particular research initiatives that could benefit at-risk or diagnosed women of all ages. For example, they specified projects within NCI's Specialized Programs of Research Excellence, which are focused on breast cancer translational research, and NCI's Breast Cancer Surveillance Consortium, which is evaluating community practice of advanced imaging technologies, such as breast magnetic resonance imaging, screening ultrasound, and a form of 3-dimensional digital breast mammography.[18] NIH officials indicated that although many of these projects and initiatives are responsive to the requirements of the EARLY Act, some were initiated prior to the act and not in response to it. The NIH officials further noted that NIH did not receive any specific EARLY Act-related funding.

Public education campaign

Since 2010, CDC reported spending about $9 million to conduct a national public education campaign to increase young women's awareness of breast health, risk factors, and early detection for breast cancer. As part of these efforts, CDC established the Advisory Committee on Breast Cancer in Young Women in 2010. The act charged the

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[17] NIH officials provided a listing of NCI supported research efforts for fiscal year 2015, which included over 500 specific research projects along with information such as the project title and number, name of principal investigator, and associated research institution.

[18] Translational research refers to translating basic research, such as laboratory research, into clinical practice by ensuring that new treatments and knowledge gained from research reach the patients or populations for whom they are intended.

committee with assisting in the creation and conduct of the education campaigns. Meeting at least once a year, this committee consists of 15 voting members, 6 non-voting ex officio members from federal agencies, and non-voting liaison representative groups. Currently, there are 12 non-voting liaison members, which represent various breast cancer related organizations.[19]

Drawing from its prevention research activities, and with input from the advisory committee, CDC developed and launched *Know: BRCA*—an interactive web resource that enables women to determine their potential risk for developing breast cancer—in 2014, and *Bring Your Brave*—a web-based campaign to educate young women at risk of or living with breast cancer—in 2015. According to CDC officials, these campaigns were launched primarily utilizing social media, such as Facebook and Twitter.

Know: BRCA offers an online assessment to help women understand their risk of having a BRCA gene mutation, and encourages them to discuss this risk with their family and medical providers. (See fig. 2.)

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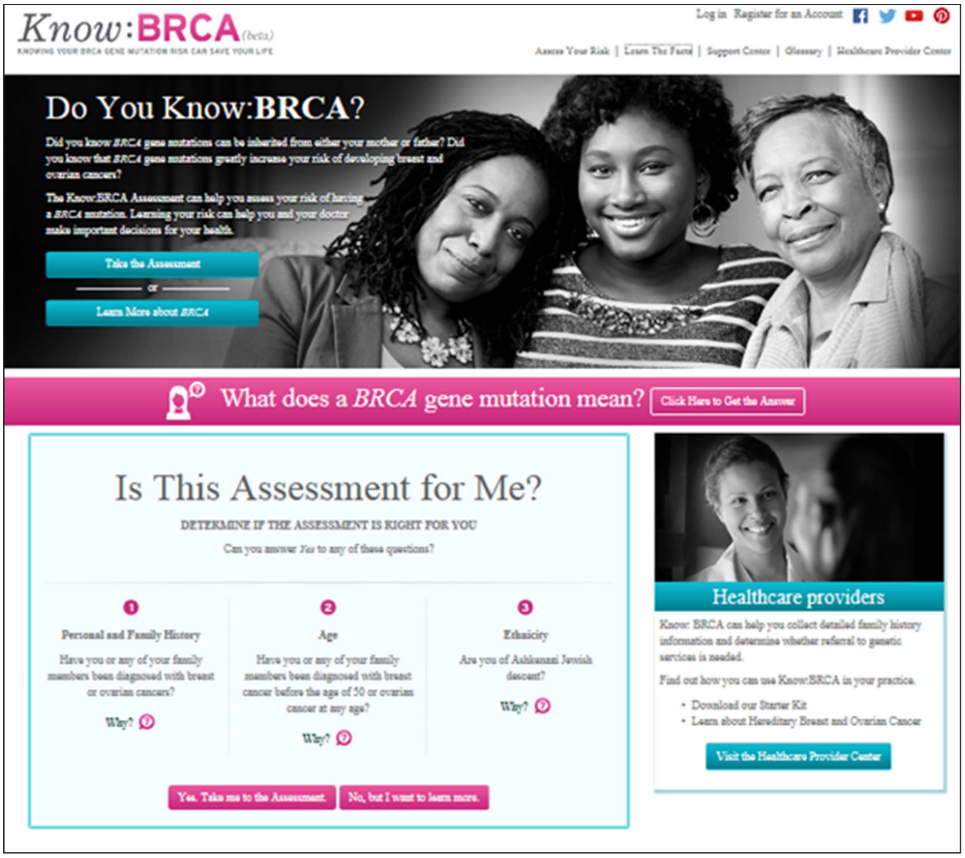
[19] The liaison groups include The Avon Foundation Breast Cancer Crusade (vacant as of August 2016); Black Women's Health Imperative; Bright Pink; LIVESTRONG, The Lance Armstrong Foundation; Living Beyond Breast Cancer; The Noreen Fraser Foundation; Patient Advocate Foundation; Sharsheret; Sisters Network, Inc.; Susan G. Komen; Tigerlily Foundation; and the Young Survival Coalition.

Figure 2: Centers for Disease Control and Prevention (CDC) *Know*: *BRCA* Website



Do You Know:BRCA?

Did you know *BRCA* gene mutations can be inherited from either your mother or father? Did you know that *BRCA* gene mutations greatly increase your risk of developing breast and ovarian cancers?

The Know:BRCA Assessment can help you assess your risk of having a *BRCA* mutation. Learning your risk can help you and your doctor make important decisions for your health.

What does a *BRCA* gene mutation mean?

Is This Assessment for Me?

DETERMINE IF THE ASSESSMENT IS RIGHT FOR YOU

Can you answer *Yes* to any of these questions?

1 Personal and Family History

Have you or any of your family members been diagnosed with breast or ovarian cancers?

2 Age

Have you or any of your family members been diagnosed with breast cancer before the age of 50 or ovarian cancer at any age?

3 Ethnicity

Are you of Ashkenazi Jewish descent?

Healthcare providers

Know: BRCA can help you collect detailed family history information and determine whether referral to genetic services is needed.

Find out how you can use Know:BRCA in your practice.

- Download our Starter Kit
- Learn about Hereditary Breast and Ovarian Cancer

Source: CDC. | GAO-17-19

Additionally, the *Bring Your Brave* campaign shares stories about young women whose lives have been affected by breast cancer. In particular, the *Bring Your Brave* website provides online videos with personal testimonials about prevention, risk, and survivorship from young women who have experienced breast cancer. The website also provides tools and templates for young women to create messages or share their stories by creating a digital “badge” that can be downloaded or shared on social media, such as Facebook or Twitter, which identify them as survivors of breast cancer. The campaign also encourages young women to learn about their risk for breast cancer, talk with their health care provider about their risk, and live a breast healthy lifestyle.[20]

Support for young women diagnosed with breast cancer

To support young women diagnosed with breast cancer, HHS awarded 14 grants—amounting to nearly $14 million in funding—from fiscal years 2010 to 2016. The purpose of these grants was to increase education and awareness, and provide support programs for young women with breast cancer. CDC awarded these grants to a range of organizations, such as small, focused research and advocacy groups, as well as large institutions and universities. Additionally, the awarded organizations developed a variety of activities to disseminate cancer information or support breast cancer survivors. For example, one research and advocacy organization used its grant to develop the Examining the Relevance of Articles for Young Survivors (XRAYS) program, which provides reviews and ratings on news articles and reports on breast cancer research to help young breast cancer survivors and at-risk women understand research that is relevant to them to make better health decisions.[21] Additionally, an institution that treats breast cancer patients used its grant to provide personalized treatment summaries and survivorship care plans for young survivors. In awarding the grants, officials stated that CDC gave priority to organizations that reach populations specifically mentioned in the EARLY Act, while following CDC's competitive and objective award protocols. For example, in its 2011 and 2014 award cycles, CDC awarded two grants to an organization that supports young Jewish women with breast cancer. One grant provided clinical support and educational resources, while the other grant was used to develop a program to provide patient navigation, peer support, genetic information, and survivorship resources.

Health professional education campaign

With reported spending of about $900,000 since 2010, efforts to develop an education campaign for health professionals are more recent and have focused on developing continuing education case studies for providers and provider components of the *Know: BRCA* and *Bring Your Brave*

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[20] According to CDC, a breast healthy lifestyle includes keeping a healthy weight, exercising regularly (at least four hours a week), limiting alcoholic drinks to no more than one per day, and avoiding exposure to chemicals that can cause cancer and interfere with the normal function of the body, among other factors.

[21] Information on the XRAYs program can be found at http://www.facingourrisk.org/XRAYS/index.php, accessed on August 12, 2016.

campaigns. For example, officials reported that CDC has ongoing efforts to educate providers through case studies, including one that addresses hereditary breast and ovarian cancer, and one that addresses how to engage young women diagnosed with breast cancer. The goal of the case studies is to help providers learn how to interpret findings, be more thoughtful about what they are seeing, and know what data should be collected. Additionally, the *Know: BRCA* assessment, which was launched in 2014, is also a clinical decision support tool that can help providers gather detailed family cancer history and identify the potential for an increased risk for the BRCA gene mutation. The tool allows this information to be downloaded directly into an electronic medical health record, and also provides clinical guidance and support resources for providers and patients. CDC officials stated that they plan to reach out to providers and interview them about their experience with the tool.

Finally, CDC officials reported that the agency is just starting efforts to develop the provider component of the *Bring Your Brave* campaign. For this effort, officials plan to learn how providers obtain health information, develop podcasts that will target these providers, and utilize social media to disseminate this information. As of August 2016, CDC officials reported that they selected a contractor that will conduct in-depth interviews and focus groups to help build messaging for providers. After the messaging is completed, CDC officials stated that they plan to discuss delivery platform options, such as various social media tools. While the EARLY Act specified that CDC should work in consultation with HRSA in educating providers, HRSA's involvement is still evolving, according to CDC and HRSA officials. HRSA and CDC have had preliminary discussions on this effort, and have indicated a commitment to working together. Specifically, HRSA indicated that it will assist in efforts to reach appropriate providers and disseminate education resources generated as a result of the EARLY Act.

HHS's Targeted Breast Cancer Education for Young Women Leverages Existing Resources, and No Evidence Suggests that These Efforts Are Duplicative

Based on our review of 17 federal websites that generated over 400 search results, we found that HHS's targeted education campaign for young women under the EARLY Act does not duplicate other documented, more general federal breast cancer education efforts.[22] Specifically, in reviewing the content of our search results, we assessed the targeted audience; whether it pertained specifically to breast cancer; and whether it was a part of an education campaign. While there are many federal resources that provide information on breast cancer, generally, they have not been focused specifically on young women and the unique issues they face. HHS's targeted campaign has leveraged some of this more general breast cancer information; however, we determined that the content of our searches was not duplicative based on targeted audience or intended purpose.

Websites such as those associated with CDC and NCI—which together generated 308 of the 400 search results—contained a significant amount of breast cancer content. At times this content overlapped with some of the breast cancer information that CDC has included in its targeted campaign; however, this information was not duplicative, because it was applicable to older women, all women, or was not related to an educational campaign.[23] For example, a search result from CDC's website entitled "CDC Prevention Checklist" contained links to an HHS website with information on women's preventive care and testing for breast cancer.[24] These links provided basic information on mammograms, speaking with a doctor about breast cancer risk, and the recommended frequency of screening for women over 40 years of age; therefore, it was not geared toward women specified in the EARLY Act. Another search

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[22] Duplication occurs when two or more agencies or programs are engaged in the same activities or provide the same services to the same beneficiaries. See GAO-15-49SP.

[23] Overlap occurs when multiple agencies or programs have similar goals, engage in similar activities or strategies to achieve them, or target similar beneficiaries. For example, NCI's website has information entitled "BRCA1 and BRCA2: Cancer Risk and Genetic Testing," which includes general information on the BRCA genes and genetic testing. This information may potentially overlap with similar information that CDC has included in its *Know: BRCA* campaign; however, overlapping information may not have a negative effect if its purpose fills gaps by providing multiple sources of information. See GAO-15-49SP.

[24] See http://www.cdc.gov/prevention/ and http://healthfinder.gov/HealthTopics/Category/doctor-visits/screening-tests/get-tested-for-breast-cancer, accessed on August 22, 2016.

result identified an NCI press release that provided research findings on a new treatment that helps young women preserve fertility during chemotherapy for breast cancer.[25] While this result presents information targeted to young women, we did not consider it duplicative, because it is not part of an education campaign.

CDC and others also reported taking steps to avoid duplicating other federal breast cancer efforts. For example, CDC's initial efforts to collect baseline information on the population and gaps in communication for young women with breast cancer through its literature review and expert panel helped ensure that it was not duplicating efforts already in place. In addition, by awarding support and education grants to organizations that had a history of educating and serving populations specified in the EARLY Act, CDC leveraged established organizations to disseminate information. For example, a national non-profit organization that supports young Jewish women facing breast cancer received one of these grants to further develop its existing programs on genetics and healthy living. A prominent cancer research institute also received a grant to expand and continue its clinical breast cancer program, which includes patient navigation and peer support for women under 45 years of age. Other efforts to leverage or build on existing information and vehicles are also evident in CDC's approach to educate health care professionals. According to a breast cancer researcher, CDC is determining who else is educating physicians so that it can build on existing continuing medical education efforts for doctors and physician assistants, rather than create a new program.

CDC officials also cited the role of the six federal agency representatives who serve as ex officio members of the advisory committee as another approach for ensuring that they are not duplicating other federal efforts.[26] According to a CDC official, ex officio members are expected to inform the advisory committee of activities within their respective agencies that may be similar or duplicative of areas that the committee may examine.

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[25] See http://www.cancer.gov/news-events/press-releases/2014/ASCOPOEMS, accessed on August 22, 2016.

[26] The six federal agencies with ex officio members on the advisory committee are Agency for Health Care Research and Quality, Department of Defense, HRSA, Indian Health Services, NIH, and HHS's Office on Women's Health.

The ex officio members also provide the advisory committee with overview presentations of their agencies' related work to make them aware of similar areas or topics of interest. An official from an organization that provides young women with education, peer support, and research indicated that the diverse members of the advisory committee talk about the work they are doing and educate each other, which helps avoid overlap and duplication. The chair of the advisory committee, who is also a breast cancer researcher and practitioner, cited the effectiveness of these efforts, but also noted that there has not been significant funding or work geared to young women with breast cancer, in part, because they are a small population.[27] According to this official, educating young women on breast cancer and supporting their unique needs are new and evolving areas, and it is not likely that such efforts are duplicative.

Agency Comments

We provided a draft of this report to the Department of Health and Human Services for comment. The department provided technical comments, which we incorporated as appropriate.

We are sending copies of this report to the appropriate congressional committees, the Secretary of HHS, and other interested parties. In addition, the report is available at no charge on the GAO website at http://www.gao.gov

If you or your staff have any questions about this report, please contact me at (202) 512-7114 or crossem@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on

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[27] This sentiment was echoed by an official from the organization that supports young Jewish women with breast cancer. This official noted that the founder of the organization, who was diagnosed with breast cancer at age 28, established the organization in 2001, because the literature and support groups that existed then did not target her age group or address her unique concerns about breast cancer as it related to her ethnicity.

the last page of this report. GAO staff who made key contributions to this report are listed in appendix I.

Marcia Crosse

Marcia Crosse
Director, Health Care

Appendix I: GAO Contact and Staff Acknowledgments

GAO Contact

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Staff Acknowledgments

In addition to the individual named above, Susan Anthony (Assistant Director), JoAnn Martinez-Shriver (Analyst-in-Charge), and Laurie F. Thurber made key contributions to this report. Also contributing were Muriel Brown, Drew Long, and Emily Wilson.

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