



IDPH

ILLINOIS DEPARTMENT OF PUBLIC HEALTH

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To the Honorable JB Pritzker, Governor
And Members of the General Assembly:

Enclosed, please find the report to the General Assembly related to “breast reconstruction and prostheses options and education” for fiscal years 2024 through 2025 pursuant to Section 2310/670 of the Civil Administrative Code of Illinois, Department of Public Health Powers, and Duties Law (Law) (20 ILCS 2310/2310).

This report details the breast cancer activities and education conducted during this period regarding the mandates, an evaluation of the extent to which the activities have been effective in improving the health of racial and ethnic minority groups, and plans for the next reporting period.

I hope you find this report informative as we work together to educate patients in Illinois about breast cancer and strive to improve the health of Illinois residents.

Sincerely,

Dr. Sameer Vohra, MD, JD, MPH
Director

PROTECTING HEALTH, IMPROVING LIVES

Background

In 2014, the Illinois General Assembly found that breast cancer has a disproportionate and detrimental impact on African Americans, is the most common cancer among the Latinx population, and that African Americans under the age of 40 have a greater incidence of breast cancer than White women of the same age. The General Assembly also found that individuals undergoing surgery for breast cancer should give due consideration to the option of breast reconstructive surgery, either at the same time as the breast cancer surgery or later. Additionally, the federal Women’s Health and Cancer Rights Act of 1998 requires health plans that offer breast cancer coverage to also provide for breast reconstruction and other sequelae of breast cancer treatment, such as lymphedema. Several states have enacted laws to require that patients receive information on their breast cancer treatment and reconstruction options.¹ According to the American Cancer Society, immediate breast reconstruction offers the advantage of combining breast cancer surgery with reconstructive surgery and is cost-effective; however, delayed breast reconstruction may be advantageous in patients who require post-surgical radiation or other treatments. A patient suffering from the loss of their breast may not be a candidate for surgical breast reconstruction or may choose not to undergo additional surgery and instead choose breast prostheses.²

In 2024, the American Cancer Society (ACS) estimated that in the United States, 313,510 (310,720 female and 2,790 male) new cases of invasive breast cancer, and about 56,500 new cases of ductal carcinoma will be diagnosed, and approximately 42,780 (42,250 female and 530 male) patients will die from breast cancer.³ Additionally, the ACS states that overall, the breast cancer death rate among females has declined by 44% as of 2020, mainly because of advances in treatment and earlier detection. This decrease translates to approximately 517,900 more averted breast cancer deaths during this period than would have been expected in the absence of this progress. Despite this progress, mortality rates in Black women remain 38% higher than in White women despite lower incidence.⁴

Based on what the Illinois General Assembly found in 2014, beginning in 2016, two years after the effective date of Public Act 98-479, the director of the Illinois Department of Public Health is required to “provide for the planning and implementation of an education campaign to inform breast cancer patients, especially those in racial and ethnic minority groups, anticipating surgery regarding the availability and coverage of breast reconstruction, prostheses, and other options.”⁵ The campaign must, at a minimum, include dissemination of the following information on IDPH’s website and other relevant state health websites: (1) breast reconstruction is possible at the time of breast cancer surgery or in a delayed fashion; (2) prostheses or breast forms may be available;

¹ https://www.cms.gov/CCIIO/Programs-and-Initiatives/Other-Insurance-Protections/whcra_factsheet

² 20 ILCS 2310/2310-670

³ www.cancer.org Breast Cancer Facts & Figures 2024-2025, page 1

⁴ www.cancer.org Breast Cancer Facts & Figures 2024-2025, page 1

⁵ 20 ILCS 2310/2310-670

(3) federal law mandates both public and private health plans to include coverage of breast reconstruction and prostheses; (4) the patient has a right to choose the provider of reconstructive care, including the potential transfer of care to a surgeon that provides breast reconstructive care; and (5) the patient may opt to undergo breast reconstruction in a delayed fashion for personal reasons or after completion of all other breast cancer treatments.⁶

In developing the information to be disseminated pursuant to Section 670 of the Law, IDPH was required to “consult with appropriate medical societies and patient advocates related to breast cancer, patient advocates representing racial and ethnic minority groups, with a special emphasis on African American and Hispanic populations’ breast reconstructive surgery, and breast prostheses and breast forms.”⁷

Based on this requirement, this report details the breast cancer activities and education carried out during this period pertaining to the mandates, an evaluation of the extent to which the activities have been effective in improving the health of racial and ethnic minority groups, and what to expect in the future for the next reporting period.

Breast Cancer Educational Materials

- The *Your Right to Know* (YRTK) publication legislation, which dates to 1995, was mandated to provide a reference document for newly diagnosed breast cancer patients, also includes information on reconstructive breast surgery and breast prosthetic options. The publication has undergone updates in 2000, 2006, and 2023. The 2023 draft received IDPH Office of Communications approval, Spanish translation, redesign, and was uploaded to the IDPH website in June 2023. Ellen Mendelson, MD, a radiology professor, revised, and redesigned the Dense Breast document (supplemental to *Your Right to Know*) to accompany the *Your Right to Know* document, and it was also uploaded to the IDPH website in June 2023.
 - In 2025, Maura Quinlan, MD, Office of Women’s Health and Family Services (OWHFS) Medical Director, who supports the OWHFS with clinical matters, including compliance with legislative mandates, coordinated initial revisions to *Your Right to Know* with clinical updates and input from the Illinois State Medical Society and IDPH Center for Minority Health. Dr. Quinlan also facilitated the initial revisions to the Dense Breast document. Phallisha Curtis, OWHFS Division Chief, will further coordinate with the IDPH Center for Minority Health and its partner network for additional insight and expertise for inclusion in the *Your Right to Know* and Dense Breast documents. Yamile’ Molina, PhD, Associate Director for Community Outreach and Health Equity at UI Cancer Center, and her team will assist with updating the two documents from the revision information provided. IBCCP personnel will update the Spanish translation of the *Your Right to Know* and Dense Breast documents, and all drafts will be submitted to IDPH Communications for approval, redesign, and uploading to the IDPH website by March 2026. Information on the IBCCP and the Illinois WISEWOMAN Program (IWP), as well as the English and Spanish versions

⁶ 20 ILCS 2310/2310-670

⁷ 20 ILCS 2310/2310-670

of *Your Right to Know* and the Dense Breast document may be found by using the links below.

- IDPH’s website (IBCCP & IWP information)
<https://dph.illinois.gov/topics-services/diseases-and-conditions/diseases-a-z-list/breast-exams-mammograms.html>
- Dense Breast (English):
<https://dph.illinois.gov/content/dam/soi/en/web/idph/files/publications/br-east-density.pdf>
- Dense Breast (Spanish):
<https://dph.illinois.gov/content/dam/soi/en/web/idph/files/publications/br-east-density-sp.pdf>
- *Your Right to Know* (English):
<https://dph.illinois.gov/content/dam/soi/en/web/idph/files/publications/yr-tk-booklet.pdf>
- *Your Right to Know* (Spanish):
<https://dph.illinois.gov/content/dam/soi/en/web/idph/files/publications/yr-tk-booklet-sp.pdf>

The information in *Your Right to Know* includes the law requirements. This includes information about specific requirements in federal law that mandate both public and private health plans including coverage of breast reconstruction and prostheses when insurers provide coverage for a mastectomy. Additionally, *Your Right to Know* includes information that breast reconstruction is possible at the time of breast cancer surgery or can be delayed, and that the patient may opt to delay breast reconstruction for personal reasons or after completion of all other breast cancer treatments. Also included is the patient’s right to choose their breast reconstruction provider while noting that there may be restrictions on insurance coverage based on plan requirements.

Summary of Educational Activities Conducted Pursuant to Section 670⁸

Breast (and Cervical) Health Education Activities Conducted During Fiscal Years 2024 and 2025

During fiscal years 2024 and 2025, the IBCCP collaborated with Southern Illinois University School of Medicine (SIUSOM) to promote relevant training opportunities related to women’s health, breast health, cancer screening, and other related topics aimed at educating and empowering Illinois providers and residents.

On September 22, 2023, the IBCCP partnered with SIUSOM to hold the **21st Annual Simmons Cancer Institute Symposium: Updates on Common Cancers and the Role of the Genetics and Immunology**

⁸ 20 ILCS 2310/2310-670

in Cancer Care. The audience included physicians, advanced practice providers, and other health care professionals interested in cancer prevention, diagnosis, treatment, and survivorship.

- **Updates on the Management of Breast Cancer**
Education included developing strategies for managing long-term breast cancer survivors in the primary care practice.
- **Treatment of Cervical Cancer in the Era of Targeted Drugs and Immunotherapies**
Education included describing how cervical cancer is diagnosed and treated and listing outcomes of treatment and possible complications.

There were 77 Symposium participants. Post-symposium survey results: 71% said the education was relevant or very relative to their practice / job, 37% stated they would make changes in their practice / job related to the education provided and 64% stated the reason they will not make changes is because they are already following recommendations / information is in line with current practices and is comparable.

On October 4, 2023, the IBCCP partnered with SIUSOM for the **20th Annual Women's Health Conference: Beyond the Uterus.** The focal audience was physicians, advanced practice providers, and other health care professionals interested in women's health care.

- **Social Determinants of Women's Health**
Education included describing the impact of the social determinants on women's health; identifying methods to evaluate the unique health needs of women in the community; and formulating a plan to begin addressing the social determinants of health; exploring different tools available to screen the social determinants of health in women.

There were 95 conference participants. Post-symposium survey results: 75.5% said the education was relevant or very relative to their practice / job needs, and 75.5% stated they would make changes in their practice / job related to the education provided.

On September 20, 2024, the IBCCP partnered with SIUSOM to hold the **22nd Annual Simmons Cancer Institute Symposium: Empowering Primary Care with Essential Insights into Cancer Management.** The audience included physicians, advanced practice providers, and other health care professionals interested in cancer prevention, diagnosis, treatment, and survivorship.

- **Breast Cancer**
Education included an overview of breast cancer to include background on BRCA1 and BRCA2 and transition to alternative genetic risk factors with familial history of cancer with focus on high risk: PALB2 or BRCA3; PTEN; TP53 and moderate risk ATM; CDH1; CHEK2; NF1; STK11.

There were 109 Symposium participants. Post-symposium survey results: 76.2% said the education was relevant or very relative to their practice / job.

On October 23, 2024, the IBCCP partnered with SIUSOM for the **21st Annual Women’s Health Conference: Understanding Normal or Not**. The focal audience was physicians, advanced practice providers, and other health care professionals interested in women’s health care.

- **Abnormal Uterine Bleeding**

Education included discussion and learning on the causes of abnormal uterine bleeding.

- **Breast Pain**

Education included discussion on symptoms and causes and issues related to breast pain.

There were 73 conference participants. Post-symposium survey results: 75.6% said the education was relevant or very relative to their practice / job needs, and 77.8% stated they would make changes in their practice / job related to the education provided.

Breast (and Cervical) Cancer Program Activities Conducted During Fiscal Years 2024 and 2025

In FY2024, the IBCCP hosted a series of three 20-minute, in-person interviews facilitated by Maura Quinlan, MD, OWHFS Medical Director. The interviews were conducted with four SIUSOM medical providers – Edem Agamah, MD, Christopher Smyre, MD, Nicole Sommer, MD, and Melanie Barnard, MD - on October 8, 2024, and October 23, 2024. The content of the interviews included genetic testing and breast cancer, screening for breast cancer, treatment, and breast reconstruction. The interviews were videoed by IDPH Communications and were posted on social media platforms for viewing by the public. The links to the videos are shown below.

Dr. Quinlan/Dr. Agamah (Genetic testing): <https://www.youtube.com/watch?v=RGr6LmsKOPQ>

Dr. Quinlan/Dr. Christopher Smyre (screening): <https://www.youtube.com/watch?v=xy0GegLsVKQ>

Dr. Quinlan/Dr. Melanie Barnard & Dr. Nicole Sommer (Breast cancer treatment & reconstruction): <https://www.youtube.com/watch?v=5QtqYINpILw>

In 2025, the IBCCP partnered with the University of Illinois Cancer Center to lead public-facing, in-person, and virtual health education events in English and Spanish, addressing African American and Latina women during months where women’s health is the focus, including October (breast cancer awareness), January (cervical cancer awareness), and May (Women’s Health, Mother’s Day). Planned upcoming events include:

1. Date / Location: October 18, 2025 - Beardstown, IL (Cass County)
Focus: Breast Reconstruction
Language / Community focus: Spanish / Latino community

2. Date/Location: November 1, 2025 – East St. Louis, IL (St. Clair County)

Focus: Breast Reconstruction

Language / Community focus: English / African American Community

3. January - Online educational event on Cervical Cancer Screenings and Prevention

4. May - Southern IL, in-person event in English focusing on Breast Density geared toward the African American community

The IBCCP will update on event outcomes in the fiscal year 2026 and 2027 General Assembly report due January 2028.

Website Access

The *Your Right to Know* publication provides educational information about breast cancer diagnoses and available treatment and test options. It includes a written summary of methods used in the early detection, diagnosis, and treatment of breast cancer. The different stages of breast cancer are explained, and information about treatment and emotional healing are provided. The publication also contains information on breast reconstructive surgery, including the use of breast implants and their potential side effects.

Table 1 shows IDPH data for the number of “views” to the IBCCP webpage and the English or Spanish *Your Right to Know* publications. Through additional marketing and an update of materials, number of visitors viewing and downloading the materials during the upcoming fiscal years are expected to increase.

Table 1: Number of Events (Views) for IDPH’s IBCCP Webpage and Breast Cancer Educational Materials, 2024 and 2025

Source Material	2024		2025	
	Total Views	Unique Visitors	Total Views	Unique Visitors
IBCCP Webpage	8,613	6,108	19,026	13,588
Your Right to Know (English)	32	31	62	60
Your Right to Know (Spanish)	4	4	6	6

Source: Illinois Department of Public Health

Next Steps

The Office of Women’s Health and Family Services will continue to work on the following in FY26 and FY27: (1) conduct biennial revisions to the *Your Right to Know* and Dense Breast publications based on feedback from the Illinois State Medical Society and minority health advocacy organizations who will review the content for effective reach to priority populations; (2) post the

documents on the IDPH website for public access; (3) partner with local organizations and academic partners to sponsor educational opportunities that provide information on the options for breast reconstruction, prosthetics and insurance coverage; (4) continue to work with the Illinois Critical Access Hospital Network and Southern Illinois University's School of Medicine to conduct training for statewide medical providers; and, (5) monitor the number of views and visits to IDPH's website for access to the IBCCP and *Your Right to Know* publications.

Conclusion

The focus will continue education and awareness efforts related to the availability and coverage of breast reconstruction, prostheses, and other options for breast cancer patients anticipating surgery, especially those in racial and ethnic minority groups. The next biennial report will include information from the IBCCP FY26 and FY27 efforts.