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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 2020 through 2021 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 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 plans for the next reporting period.

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

Sincerely,

*Sameer Vohra*

Sameer Vohra, MD, JD, MA  
Director

## Background

In 2014, the Illinois General Assembly found that breast cancer has a disproportionate and detrimental impact on African Americans under 40 years of age who have a greater incidence of breast cancer than White women of the same age and is the most common cancer among the Latinx population. The General Assembly also observed 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, other sequelae of breast cancer treatment, such as lymphedema. Several states have enacted laws to require patients receive information on their breast cancer treatment and reconstruction options.<sup>1</sup> According to the American Cancer Society, immediate breast reconstruction offers the advantage of combining the breast cancer surgery with the reconstructive surgery and is cost effective. However, some patients 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.<sup>2</sup> For others delayed reconstruction may be advantageous if they require post-surgical radiation or other treatments.

In 2021, the American Cancer Society (ACS) estimated that in the United States 281,550 new cases of invasive breast cancer and about 49,290 new cases of ductal carcinoma will be diagnosed; and about 43,600 patients will die from breast cancer.<sup>3</sup> Additionally, the ACS states that overall, White people are slightly more likely to develop breast cancer than Black people, although the gap between the two races has closed in recent years. In individuals under 45 years of age, breast cancer is more common in Black people according to ACS. Black people are also more likely to die from breast cancer at any age.<sup>4</sup>

Based on the Illinois General Assembly findings 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."<sup>5</sup> The campaign must, at a minimum, include dissemination of the following information on the IDPH 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

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<sup>1</sup> 20 ILCS 2310/2310-670

<sup>2</sup> [https://www.cms.gov/CCIIO/Programs-and-Initiatives/Other-Insurance-Protections/whcra\\_factsheet](https://www.cms.gov/CCIIO/Programs-and-Initiatives/Other-Insurance-Protections/whcra_factsheet)

<sup>3</sup> <https://www.cancer.org/content/dam/CRC/PDF/Public/8577.00.pdf>

<sup>4</sup> <https://www.cancer.org/content/dam/CRC/PDF/Public/8578.00.pdf>

<sup>5</sup> 20 ILCS 2310/2310-670

available; (3) federal law mandates both public and private health plans 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.<sup>6</sup>

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.”<sup>7</sup>

Based on the requirement, this report details the breast cancer activities and education carried out during this period pertaining to the mandates, as well as 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 next reporting period.

## Breast Cancer Educational Materials

The *Your Right to Know* (YRTK) booklet legislation dates to 1995 and has undergone updates in 2000 and 2006. The booklet was mandated to provide a reference document for newly diagnosed breast cancer patients. The booklet also includes information on reconstructive breast surgery and breast prosthetic options. In 2008, IDPH consulted with the Southern Illinois University (SIU) School of Medicine to update the YRTK booklet in response to changes in breast cancer care for screening, diagnosis, and treatment (20 ILCS 2310/2310-345), available online in both English and Spanish. IDPH is currently working with the Illinois Breast and Cervical Cancer Program’s (IBCCP) contracted breast health consultant from Northwestern Medicine to update the booklet to ensure the information represents the most current developments and research in breast cancer screening, diagnosis, and treatment options. The booklet’s final draft is expected to be released in FY23. Additionally, educational information on breast cancer, the IBCCP, and the Illinois WISEWOMAN Program can be found on IDPH’s website at <https://dph.illinois.gov/topics-services/life-stages-populations/womens-health-services.html>).

The information in YRTK was updated to include the new requirements of the law. This includes information about specific requirements in federal law that mandate both public and private health plans include coverage of breast reconstruction and prostheses when insurers provide coverage for a mastectomy. Additionally, the updated version of YRTK 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 postpone breast reconstruction for personal reasons or wait for the completion of all other breast cancer treatments. Also included is the patient’s right to choose

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<sup>6</sup> 20 ILCS 2310/2310-670

<sup>7</sup> 20 ILCS 2310/2310-670

their breast reconstruction provider and a notation that there may be restrictions on insurance coverage based on plan requirements.

IDPH will work with the University of Illinois Chicago and IDPH's Office of Minority Health and Comprehensive Cancer Control Program to identify groups to review the updated materials for language, readability, and value of information. Information collected will inform any updates needed to the materials to make them as effective as possible for priority populations inclusive of African American, Hispanics, and Asians. The final draft of the booklet is planned for FY23.

## Summary of Educational Activities Carried Out Pursuant to Section 670<sup>8</sup>

### *Breast (and Cervical) Health Education Activities Carried Out During FY20 and FY21*

IBCCP offers free mammograms, breast exams, pelvic exams, and pap tests to eligible Illinois residents, and has been providing breast and cervical cancer screenings since 1995. During FY20 and FY21, IBCCP collaborated with the Illinois Critical Access Hospital Network and SIU School of Medicine to promote relevant training opportunities related to women's health, breast health and cancer screening, and other related topics aimed at educating and empowering Illinois residents.

On September 13, 2019, SIU School of Medicine hosted a symposium to examine the impact of new molecular genetics on the care of cancer patients, as well as the costs to patients, their families, and society. For each of the personalized cancer care topics, speakers presented a case vignette and discussed the pathology, molecular genetics, aspects of early detection and screening, diagnosis, treatment, complications of treatment and impact on quality of life, survivorship, cancer rehabilitation, and financial impact. The objectives of the training were to have participants be able to define financial toxicity regarding cancer care, to describe the impact of a cancer diagnosis on a patient's financial status, and to describe the socio-economic impact of cancer diagnosis and treatment on patients and their families. Additionally, participants were introduced to genetic tests used to make decisions about cancer diagnosis and treatment, identify the cost/benefit of these new procedures for patients, and list available resources, including disability insurance, to assist patients with the financial burden of cancer. The symposium attracted 114 participants, including 53.5% who were medical providers. The symposium provided content that helped participants understand how to engage with patients about the impact of financial stress on cancer care and the use of genetics to inform cancer screening, diagnostics, and treatment. The symposium gave participants a better perspective on the financial and clinical issues patients encounters with a cancer diagnosis and how they can assist them in navigating their options.

On October 2, 2019, SIU School of Medicine hosted a training event focusing on several topics. The session entitled "Getting to Know You: The Power of Story," engaged the participants in an exercise that enabled them to identify their core values that can form the basis for powerful

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<sup>8</sup> 20 ILCS 2310/2310-670

narratives about self-worth. They also provided training on motivational interviewing techniques that focused on the benefits of motivational interviewing and how to use 3 to 5 specific motivational interviewing skills in a health care setting. The event reached 156 participants, including 73.7% of whom were medical providers, and focused on helping participants engage with patients on being their best health advocates in clinical settings.

On May 6, 2020, the Illinois Critical Access Hospital Network provided a training opportunity for IBCCP staff entitled: "Genetic Assessment and Treatment of Breast Cancer" that focused on genetic testing as a valuable tool in the assessment and treatment of breast cancers. The webinar explored the relationship between breast cancer and genetic predisposition and current directions in research that are applicable to medical providers and their patients. The training described inherited conditions causing the risk for breast cancer, reviewed current genetic screening, and testing recommendations for breast cancer, and explored future directions in genetic evaluation for breast cancer. The session had 81 attendees who were given training to improve their understanding of the role of genetics in breast cancer treatment and how to counsel patients in their treatment options. The IBCCP seeks to train cancer care providers.

In FY21, IBCCP again partnered with the SIU School of Medicine and the Illinois Critical Access Hospital Network to offer relevant and timely training opportunities.

Southern Illinois University School of Medicine provided a series of online modules covering a wide range of topics that were made available in FY21 to IBCCP staff and interested public. Module topics included genetic breast cancer risk assessment and management, cervical cancer, dysplasia, colposcopy, COVID-19, and cancer. Genetic breast cancer risk assessment and management focused on the importance of a comprehensive, multi-generational family history to understand risk, an overview of genetically mediated breast cancers, and discrimination related to genetic cancers. The series on cervical cancer, dysplasia, and colposcopy focused on tailoring risk assessments to individual patients, addressing abnormal Pap smear results, and colposcopy indications and performance. The final module concentrated on COVID-19 and cancer. This covered the impact of COVID-19 on screening rates both nationally and locally, the impact of COVID-19 on cancer treatment schedules, strategies to improve patient screening, and subsequent treatment during COVID-19, including telehealth. The training series was intentional in informing the provider network on how to engage with patients on their breast cancer risk and how it impacts their screening and treatment options inclusive of reconstruction.

The Illinois Critical Access Hospital Network presented training on breast health in June 2021. The training focused on providing participants with a greater understanding of issues related to breast health, breast imaging, and breast cancer in women of all age groups. The training described breast imaging findings using digital mammography, ultrasound, and MRI. Also discussed was the use of tamoxifen in breast cancer prevention in women with hyperdense breasts and current concepts for ductal carcinoma in situ (DCIS), invasive ductal carcinoma, and tumor markers and prognosis. The 86 persons in attendance received guidance needed to help patients understand screening options and results interpretation so they can advocate for the best course of action in their care.

The Illinois Critical Access Hospital Network also provided a training entitled “Applying Motivational Interviewing Skills to Promote Health Screenings and Health Behaviors” in June 2021. The training focused on how to apply motivational interviewing tools during client encounters to promote healthy behaviors. The training explained the basic principles and spirit of motivational interviewing, discussed when motivational interviewing communication skills are most useful during a client encounter, and developed strategies for applying motivational interviewing skills in practice. The IBCCP seeks to build an empathic cancer care network that helps patients make the best health decisions for their care.

### *Illinois Breast and Cervical Cancer Program Activities Carried Out During FY20 and FY21*

In 2020 and 2021, IBCCP continued to provide opportunities for IBCCP lead agencies to focus on an evidence-based interventions (EBI’s) aimed at increasing screening. Many of the projects centered on barrier reduction for screening services, such as provider and client reminders, provider and client education, transportation assistance, and partnerships with local pharmacies for public education on the program and its services. All IBCCP lead agencies completed EBI’s, collected data on the effectiveness of the project, and provided final reports highlighting outcomes. The projects ranged from connecting with underserved populations to assessing provider performance in referring patients for appropriate screenings. Outcomes were shared with lead agencies to provide an opportunity to learn from their peers. The goal of the EBI was to increase screening through evidenced informed activities to include education and awareness using small media tools, trusted partnerships, and screening reminders. Early detection leads to better outcomes and knowledge of treatment and options for breast reconstruction.

IBCCP also continued the development of the Community Navigation program component. This program component focused on supporting lead agencies to hire personnel to complete select EBI’s that concentrated on community outreach and engagement. Additional EBI work emphasized provider education and performance as well as partnering with local organizations, businesses, and insurance groups to improve access to screening services. Community navigators worked to reach populations that were not being contacted through regular means to encourage prevention and early intervention. Community navigators also partnered with providers to provide education and support to ensure patients are referred to IBCCP when appropriate. The Community Navigation program component has grown since its inception in 2018 with the original three lead agency sites. There are currently 11 active community navigation sites with three additional sites working to hire community navigators. The community navigators are trained in emotional interviewing, trauma informed care, and readiness for change to engage with individuals on the benefits of breast and cervical cancer screening. They also engaged with employers and insurers to explain the return on investment for policies that enabled individuals to seek and to obtain screening services. The community navigators take every opportunity to engage with the public on the screening benefits and improved outcomes for treatment inclusive of reconstruction.

## Website Access

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

Table 1 shows IDPH data for the number of events or “views” to the IBCCP webpage and the individual educational publications indicated below. Through additional marketing and an update of materials, it is anticipated there will be an increase in the number of visitors viewing and downloading the materials during the upcoming fiscal year.

**Table 1: Number of Events (Views) for IDPH’s IBCCP Webpage and Breast Cancer Educational Materials, 2020 and 2021**

Source Material	2020		2021	
	Total Events	Unique Events	Total Events	Unique Events
IBCCP Webpage	1,120	962	2,253	2,060
Your Right to Know (English)	76	59	58	45
Your Right to Know (Spanish)	32	29	40	33

Source: Illinois Department of Public Health

## Next Steps

The Office of Women’s Health and Family Services will continue to work on the following for FY22 and FY23: (1) finalize revisions to the *YRTK* booklet and dense breast brochure based on feedback from the program’s breast health consultant, Illinois State Medical Society, and minority health advocacy organizations that will review the content for effective reach to priority populations; (2) post the documents on the IDPH website for public use; (3) partner with local organizations to sponsor public town halls and educational opportunities to provide information on the options for breast reconstruction, prosthetics and insurance coverage; (4) continue to work with the Illinois Critical Access Hospital Network and SIU School of Medicine to conduct training for statewide medical providers; and, (5) monitor the number of visits to IDPH’s website and to download the pre- and post-revision *YRTK* booklet to determine effective ways of reaching and educating women once the pending revisions to the booklet are completed and the results are uploaded.

## Conclusion

IDPH will continue its focus on 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 data for FY22 and FY23.