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May 12, 2021

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 2018 through 2019 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 aforementioned mandates, an evaluation of the extent to which the activities have been effective in improving the health of racial and ethnic minority groups, and future 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,

Ngozi O. Ezike, MD
Director
Illinois Department of Public Health

Background

In 2014, the Illinois General Assembly noted breast cancer has a disproportionate and detrimental impact on Black people, it is the most common cancer among the LatinX population, and Black people under the age of 40 have a greater incidence of breast cancer than White people of the same age. The General Assembly also observed 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 at a later date. Additionally, the Federal Women’s Health and Cancer Rights Act of 1998 requires health plans that offer breast cancer coverage to provide for breast reconstruction, other sequelae of breast cancer treatment, such as lymphedema. Several states have also enacted laws to require 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 2021, the American Cancer Society (ACS) estimates 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 cancer³. Additionally, the ACS states that overall, White people are slightly more likely to develop breast cancer than Black people, although the gap between them has been closing in recent years. In individuals under age 45, breast cancer is more common in Black people, and they are also more likely to die from breast cancer at any age.⁴

Based on what the Illinois General Assembly learned 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 (IDPH) 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

¹ 20 ILCS 2310/2310-670

² https://www.cms.gov/CCIIO/Programs-and-Initiatives/Other-Insurance-Protections/whcra_factsheet

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

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

⁵ 20 ILCS 2310/2310-670

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; (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 that requirement, this report details the breast cancer activities and education carried out during this period pertaining to the aforementioned 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 future plans for the next reporting period.

Breast Cancer Educational Materials

In 2018 and 2019, the IDPH Illinois Breast and Cervical Cancer Program (IBCCP) developed a number of educational materials and, in collaboration with the University of Illinois Cancer Center, Office of Community Engagement and Health Equity (CEHE), developed a Community Navigation Toolkit. This toolkit supported community navigators in developing strategies to connect community members to local clinics to increase access to cancer prevention and early intervention services.

Also, as a part of the health systems intervention pilot (described below in Other Activities Carried out During 2018-2019) conducted with UI Health Mile Square Health Center – Back of the Yards Clinic, staff developed bilingual, plain language, culturally targeted education cards that describes: 1) what happens when an individual gets a screening mammogram, 2) what happens after an individual gets a mammogram, and 3) what could happen during a diagnostic mammogram. The purpose was to promote patient education and to mitigate psychosocial stress factors associated with screening.

Additionally, educational information on breast cancer, IBCCP, and the Illinois WISEWOMAN Program (IWP) can be found on the IDPH website.

Finally, IBCCP lead agencies were also provided CDC infographics to distribute that describe breast cancer rates, mortality rates, risk factors, and the benefits of screening.

⁶ 20 ILCS 2310/2310-670

⁷ 20 ILCS 2310/2310-670

Summary of Educational Activities Carried Out Pursuant to Section 670

Educational Activities Carried Out During Fiscal Years 2018 and 2019

IBCCP offers free mammograms, breast exams, pelvic exams, and Pap tests to eligible Illinois residents⁸, and has been providing breast and cervical cancer screenings to Illinoisans since 1995. During fiscal years (FY) 2018 and 2019, IBCCP collaborated with Illinois Critical Access Hospital Network (ICAHN) and Southern Illinois University's (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.

In 2018, IBCCP staff collaborated with ICAHN to provide breast health and cancer screening training that covered how to identify patient-provider communication strategies to increase screening and prevention and to provide a review of appropriate screening guidelines for breast and preventable cancers. This training also described strategies for management of early breast cancer.

In 2018, IBCCP staff teamed with SIU School of Medicine to offer several trainings. In May, Updates in Primary Care training was provided that compared and contrasted the differences between traditional ultrasound studies from the radiology department compared to point of care ultrasound in the primary care office.

In September 2018, SIU School of Medicine provided Passport to Shared Care training. This training identified common problems that are potentially worrisome for cancer and need further investigation, described diagnostic investigations that are needed to establish a cancer diagnosis, described how to deal with the stress and fear surrounding the uncertainty of cancer diagnosis, and how to appropriately handle the "no cancer" diagnosis. The training also described a case of a breast cancer patient who experienced a lapse in communication; identified appropriate follow-up and survivorship strategies, including those to improve communication; and identified key points of basic science relevant to the case. Finally, this training covered cancer survivorship, how to define shared care and review the American Society of Clinical Oncology (ASCO) model, and identified strategies to successfully implement shared care.

In October 2018, SIU School of Medicine provided Challenges of Women's Health Care training. The training covered the challenge of restoring female sexual function after cancer treatment as well as the challenges of chronic disease management in patients with cancer.

In 2019, IDPH IBCCP staff collaborated with ICAHN to deliver two webinars. In April 2019, ICAHN hosted a Patient Navigation webinar, which described the importance of patient

⁸ Eligible women are women who live in Illinois, do not have insurance, and are between the ages of 35 and 64, although younger women may be eligible in some cases.

navigation through the continuum of care. The following month ICAHN hosted a breast health webinar, which described evidence-based breast health resources that can guide care.

In 2019, IBCCP staff collaborated with SIU School of Medicine to provide several trainings. In September 2019, SIU hosted the 18th Annual Simmons Cancer Institute Symposium: Cancer Care in the Era of Personalized Medicine, which covered:

- The Landscape of Financial Toxicity in Cancer Care
- Molecular Evolution of Cancer Care: Breakthroughs at a Cost
- Personalized Breast Cancer Care

Additionally, in October 2019, SIU School of Medicine hosted the 17th Annual Women's Health Conference: What about Me? Empowering Women to Prioritize Self Care.

Other Activities Carried Out During Fiscal Years 2018 and 2019

IBCCP activities during 2018 and 2019 were wide ranging and targeted a variety of goals and objectives. IBCCP presented at the Illinois Department of Healthcare and Family Services (HFS) quarterly Manage Care Organization (MCO) meetings to address strategies to improve breast cancer screening. Additionally, IBCCP sponsored meetings with high school seniors to give insight and guidance on pursuing careers in public health through higher education. IBCCP's health educator also facilitated breast health and screening education courses for inmates at the Logan Correctional Center.

IBCCP partnered with the UI Health Mile Square Health Center – Back of the Yards Clinic on the health systems intervention pilot to develop and to implement evidence-based interventions aimed to increase access to screening and to treatment. This intervention included a focus on education and outreach to uninsured and underinsured community members. Efforts consisted of conducting short information sessions with all staff members to inform them about programing that offers screening and diagnostic services for uninsured and under-insured women at no cost. Flyers or information cards were given to staff and provided in the clinic waiting room. Finally, the efforts included development of a breast and cervical cancer screening workflow chart. The chart describes each component of the screening process and has spaces to indicate which personnel or personnel type is responsible for respective components.

Website Access

The *Your Right to Know (YRTK)* booklet provides education 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 to emotional healing is provided. The publication contains information on breast reconstructive surgery, including the use of breast implants and their potential side effects.

In past reports, IDPH was able to show data for the number of events or “views” to the IBCCP webpage and individual educational publications. Unfortunately, we were unable to pull this data for the 2018 and 2019 fiscal years due to staffing demands related to the COVID-19 pandemic. IDPH intends to include data related to fiscal years 2018, 2019, 2020, and 2021 in the subsequent biennial report.

Next Steps

The IDPH Office of Women’s Health and Family Services (OWHFS) will seek partnerships with organizations, such as the Komen Foundation, Northwestern Medicine, the American Cancer Society, and the Illinois State Medical Society, to develop educational materials that provide information on breast reconstruction and prostheses and are targeted to racial and ethnic minorities after breast cancer treatment. The messaging will be culturally appropriate and provide guidance on accessing these medical services as part of the continuum of care.

OWHFS will continue to concentrate on the following for FY 2020 and FY 2021: (1) finalize revisions to the *YRTK* booklet based on feedback from the program’s breast health consultant; (2) encourage IBCCP lead agencies to disseminate the revised booklet to all breast cancer clients once finalized; (3) continue to collaborate with the University of Illinois School of Public Health to create topic-specific one-page educational handouts on [breast care](#) to post on the IBCCP and Illinois WISEWOMAN (IWP) webpages of IDPH’s website, which was delayed during the previous reporting period; (4) partner with 2-to-3 IBCCP lead agencies located in hospital settings that provide treatment to conduct a small educational campaign on reconstructive surgery options, which was delayed during the previous reporting period; (5) collaborate with HFS on the Refer to Treatment Act program to obtain data on the number of breast prostheses provided to IBCCP breast cancer clients; (6) continue to work with ICAHN to conduct trainings for statewide medical providers on breast health education and reconstruction in the third and fourth quarter of the fiscal year 2021; and (7) monitor the number of visits to IDPH’s website to view and to download the pre- and post-revision *YRTK* booklet to determine effective ways of reaching and educating women once the booklet is completed, and the results are uploaded.

Conclusion

We will focus our attention 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 FY 2020 and FY 2021.