**[SAMPLE] Hospital and Medical Center Cancer Genetics Data Report [year(s) of data reported] on Potential Hereditary Breast and Ovarian Cancer Syndrome-Related Cancers**

This report prepared by [] provides information on the number of patients at your facility and statewide who may be at risk for Hereditary Breast and Ovarian Cancer syndrome (HBOC), based on data that were reported to the central cancer registry from your institution during the time period mm/yyyy to mm/yyyy. **The cases listed below are cancers in patients who might benefit from further evaluation for referral to genetic counseling but are not confirmed to be HBOC-associated.1**

**How many patients***†* **were identified at [reporting institution] and statewide?**

Number of cancers diagnosed during [Timeframe] in [Location] patients who could have Hereditary Breast and Ovarian Cancer syndrome (HBOC)

| Cancer Site | Sample (Facility specific)*†* | Entire State |
| --- | --- | --- |
| Female Breast (≤ Age 45)\* | # of cases | # of cases |
| Female Breast (≤ Age 50)\* | # of cases | # of cases |
| Triple Negative Female Breast (≤ Age 60) | # of cases | # of cases |
| Ovary, Fallopian Tube, or Peritoneum (All Ages) | # of cases | # of cases |
| Male Breast (All Ages) | # of cases | # of cases |
| Multiple Primary Breast Tumors | # of cases | # of cases |

Source: [insert data source]

*†Patient names associated with the reported diagnoses can be sent to a designated person in your facility upon request. If requested, the names will be disclosed to your facility using current confidentiality rules.*

*\*Breast cancer at age 45 or younger is sufficient for referral to genetic counseling based on some recommendations, unlike breast cancer at age 50 or younger which requires that certain family health history criteria be met. Thus, female breast cancer at age 45 or younger can be reported separately from female breast cancer at age 50 or younger.*

**What is HBOC?** HBOC is a genetic condition that increases an individual’s risk for breast, ovarian, and other cancers. HBOC is most often caused by mutations in the *BRCA1* and *BRCA2* genes.

**What are the benefits of identifying individuals with HBOC?** Identifying patients with HBOC is important because steps can be taken to detect cancer earlier if it develops and reduce cancer risks in the future for the patients and their relatives. Patients with breast or ovarian cancer who are diagnosed with HBOC have a higher risk for developing future cancers and can benefit from prophylactic surgery, chemoprevention, or closer monitoring.Family members of these individuals might have HBOC and should consider genetic counseling and testing for the same mutation identified in the patient.

**How can cancer registry data help identify individuals with HBOC?** Patients with certain types of cancer are more likely to have *BRCA* mutations. These patients can be readily identified from cancer registry data and could benefit from evaluation for referral to genetic counseling. These include patients with:

* Early onset female breast cancer (diagnosed at or before age 50)
* Triple negative breast cancer (estrogen receptor (ER) negative, progesterone receptor (PR) negative, and human epidermal growth factor receptor 2 (HER2) negative, diagnosed at or before age 60)
* Ovarian, tubal, or pertoneal cancer (diagnosed at any age)
* Male breast cancer (diagnosed at any age)
* Multiple primary breast tumors in the same patient, especially if one is diagnosed before age 50

In evaluating whether a referral to genetic counseling is appropriate, the patient’s age, cancer family health history, and tumor marker information can be considered. Resources, such as the [*Know*:BRCA](https://www.knowbrca.org/) tool and others, are available to assist with evaluation for referral to genetic counseling.

**Can cancer registry data identify all patients with HBOC?** Not all patients with HBOC can be identified through cancer registry data. Most cancer registries do not include family health history information, so individuals more likely to have HBOC due to their family health history might not be identified. Current recommendations from the U.S. Preventive Services Task Force (USPSTF)2 focus on identification of women with a family health history of breast and ovarian cancer who have not had HBOC-related cancer themselves. While cancer registries will not identify these individuals, cancer registry data provide a mechanism to reach an affected family member, who is the preferred candidate for initial genetic testing in a family.

**Will insurance cover genetic counseling and testing for individuals identified as more likely to have HBOC through the cancer registry?** The Centers for Medicare and Medicaid Services (CMS) Local Coverage Determination (LCD) on *BRCA1* and *BRCA2* Genetic Testing allows for regional coverage of *BRCA* genetic counseling and testing for individuals with personal histories of breast, ovarian, and other cancers that fit specific criteria for increased risk for a *BRCA* mutation. The Affordable Care Act requires non-grandfathered health plans to cover without cost sharing preventive services with a USPSTF rating of “B” or higher, which includes the *BRCA* testing recommendation. However, the USPSTF recommendation only addresses genetic counseling and testing in women without a personal history of HBOC-related cancer, so it does not apply to affected individuals identified through the cancer registry but might cover testing for some of their relatives.

Reference

1. National Comprehensive Cancer Network. NCCN Guidelines Version 2.2014 Genetics/Familial High-Risk Assessment: Breast and Ovarian. MS3-8.
2. U.S. Preventive Services Task Force. Risk Assessment, Genetic Counseling, and Genetic Testing for BRCA-Related Cancer in Women: U.S. Preventive Services Task Force Recommendation Statement. Ann Intern Med. 2014;160:271-281.