**[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, 2**

**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 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 |
| Pancreas (All Ages) | # of cases | # of cases |
| Prostate with Gleason Score ≥ 7 or Metastatic (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.*

**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 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 peritoneal cancer (diagnosed at any age)
* Male breast cancer (diagnosed at any age)
* Pancreatic cancer (diagnosed at any age)
* Metastatic or high grade (Gleason score ≥7) prostate cancer
* 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. Tools, such as those listed in the [USPSTF recommendation](https://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/brca-related-cancer-risk-assessment-genetic-counseling-and-genetic-testing1), 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. However, cancer registry data provide a mechanism to reach an affected family member, who is the preferred candidate for initial genetic testing in a family. Once a person with HBOC is identified, cascade testing can be used to find other at-risk family members.

**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. The [USPSTF](https://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/brca-related-cancer-risk-assessment-genetic-counseling-and-genetic-testing1) recommends that primary care providers screen women with a personal or family history of breast, ovarian, tubal, or peritoneal cancer or who have an ancestry associated with *BRCA* gene mutations with one of several screening tools designed to identify a family health history with an increased risk for potentially harmful mutations in breast cancer susceptibility genes. Women with positive screening results should receive genetic counseling and, if indicated after counseling, genetic testing.

References

1. National Comprehensive Cancer Network. NCCN Guidelines Version 3.2019 Genetics/Familial High-Risk Assessment: Breast and Ovarian.
2. U.S. Preventive Services Task Force. Risk Assessment, Genetic Counseling, and Genetic Testing for BRCA-Related Cancer: U.S. Preventive Services Task Force Recommendation Statement. JAMA. 2019; 322:652-655.