# COLORADO

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## A Novel Approach to Ensure Cancer Patients Receive Genetic Services

# NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

**SUMMARY**: The Colorado Central Cancer Registry (CCCR) developed a new service to provide to reporting hospitals. In a pilot project, the CCCR provided lists of patients back to reporting hospitals which identified patients who may be at increased risk of either Hereditary Breast and Ovarian Cancer or Lynch syndrome. The goal of the project is to help hospitals ensure that patients who need genetic services have been referred.

**CHALLENGE:** Approximately 5-10% of cancers are due to genetic mutations and patients and their families can benefit from understanding their genetic risk. Families with known genetic mutations or syndromes may have modified screening schedules and those individuals who carry a mutation could further benefit from prophylactic treatments to reduce the risk of developing cancer. However, a substantial proportion of cancer patients do not obtain genetic counseling and/or testing.

**SOLUTION:** Central cancer registries can use the data they collect to help identify patients who may be at risk for genetic syndromes. The Colorado Central Cancer Registry developed a SAS® software program to analyze data to determine which patients met National Comprehensive Cancer Network (NCCN) guidelines (https://www.nccn.org/professionals/physician_gls/default.aspx) for referral to genetic counseling based on risk criteria for Lynch syndrome or Hereditary Breast and Ovarian Cancer (HBOC). Sending this information back to the hospitals that reported the cancer provides one avenue for ensuring that patients are referred for genetic services.

**RESULTS:** Three Colorado hospitals agreed to participate in the pilot project. For each hospital, CCCR produced a listing of their patients who met NCCN criteria for genetic counseling referral. The specific criteria we used were:

| Registry criteria |
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| HBOC |
| Breast cancer <=50 |
| Two breast cancer primaries |
| Breast cancer <=60 that is triple negative for ER/PR/Her2 |
| Male breast cancer |
| Ovarian cancer at any age (epithelial, non-mucinous) |
| Metastatic prostate cancer (Summary Stage 4-7) |
| Ashkenazi Jewish decent with breast, ovarian or pancreatic cancer at any age |
| Breast and pancreas any age |
| Lynch Syndrome |
| CRC or endometrial <50 |
| CRC or endometrial at any age that is MSI unstable or MMR gene deficient |
| CRC or endometrial with metachronous or synchronous LS cancer* |

*CRC, endometrial, gastric, ovarian, pancreas, ureter and renal pelvis, brain (usually glioblastoma), small intestine, as well as sebaceous adenoma, sebaceous carcinoma and keratoacanthomas as seen in Muir-Torre Syndrome.

CCCR sent each patient list to either the genetic counselor or the tumor registry based on hospital preference. Each hospital reviewed the list and determined which patients had already been referred to counseling, and which patients received counseling and/or genetic testing. Overall, the three hospitals discovered that only about half of patients who are at risk for Lynch syndrome or HBOC are being referred for genetic services. However, all three hospitals found a significant disparity with those at risk for Lynch syndrome: only about 20% are being referred for genetic services. Each hospital is now in the process of evaluating their policies, operations and practices to ensure that patients who need genetic services get appropriate, timely care.

**SUSTAINING SUCCESS:** This project is sustainable with very few required resources on the part of the central cancer registry. Two additional hospitals requested patient lists and are reviewing them now. Further, hospitals that choose to participate in this project can use it to help meet American College of Surgeons Commission on Cancer accreditation requirements for quality improvement. Central cancer registries can provide this service to their reporting hospitals on an ongoing basis to help hospitals ensure that their patients are receiving the genetic services they need, and to eventually help the family members of those patients to take steps to reduce their risk of developing cancer or to find it at the earliest possible stage.


Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion

CS 305598-A