Collaborating with

Central Cancer Registries for Public Health Genomics

Central cancer registries make up a comprehensive national network of population-based cancer surveillance to monitor cancer cases at local, state, and national levels. These registries provide complete, timely, and quality cancer data that can be used to plan, implement, and evaluate cancer prevention and control programs. Cancer registries can be used to identify populations that would benefit from enhanced cancer screening and outreach efforts. This guide provides examples of how state health departments have collaborated with cancer registries to inform and implement activities in cancer genomics to meet the special needs of people at risk of hereditary cancers.

BACKGROUND

CDC's Cancer Genomics Program has funded several state health departments to implement education, surveillance, and policy and systems change activities addressing Hereditary Breast and Ovarian Cancer syndrome (HBOC) and Lynch syndrome (LS). Cancer registries have been critical partners for implementing activities in cancer genomics. The Cancer Registries Amendment Act requires health care facilities and practitioners to report newly diagnosed cancer cases to cancer registries supported by CDC's National Program of Cancer Registries (NPCR) and/or the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program. While some data are required by these programs, individual registries can collect additional data to meet priorities and interests unique to their state.

In this guide, we describe approaches for collaboration with cancer registries and provide examples of how funded recipients have implemented them and lessons learned. Each approach highlights **potential resources required, challenges, and outputs or outcomes** from implementing that specific activity.

ANALYSIS OF CANCER REGISTRY DATA

Resources	Challenges	Outputs/Outcomes
• Costs for data access • Staff time • Data use agreement and other registry requirements	• Barriers to accessing data • Wait time for accessing data	• Estimated incidence and burden of hereditary cancers • Data for program planning

Analyzing cancer registry data can help states estimate the incidence and burden of cancers, including those that may increase risk of carrying a pathogenic mutation. State health departments can develop criteria to query their registry data using national recommendations, such as those outlined by the **United States Preventive Services Task Force (USPSTF)** and the **National Comprehensive Cancer Network (NCCN)**. These guidelines provide personal and family history criteria that can help states estimate the number of newly diagnosed cancer patients who may be at increased risk for carrying a pathogenic genetic mutation and may have benefitted from genetic counseling and testing as part of their diagnostic process. Findings can be used in health education materials, for policy and systems change activities, or to tailor activities to the needs of each state.

The resources needed to analyze cancer registry data may depend on states' policies for access to and analysis of data. Some cancer registries charge fees for data access and analysis, require data use agreements, or have other requirements (for example, the submission and approval of data analysis plans). Some have specific requirements for accessing, using, and presenting cancer registry data. For example, cancer registries may have policies based on level of geography, suppression of small cell sizes, stratification by key variables such as race or ethnicity, and presentation of results.

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Michigan

Michigan analyzed its state cancer registry data annually to monitor annual rates and trends of cancer incidence and deaths that may be associated with HBOC and LS based on NCCN guidelines. These analyses allowed Michigan to understand its state's hereditary cancer burden, assess disparities, and measure the program's impact over time. The state genomics program paid a nominal fee for data access and submitted an annual data use agreement. The approval process took 6 to 8 weeks. Epidemiologist and cancer registry staff time were necessary to clean and analyze data and disseminate results.

Each year Michigan analyzed the data, created **a report** and shared it broadly with internal and external partners. Through presentations at scientific conferences and meetings, the program shared its findings with broader audiences. The data were also used for program planning. For example, findings were used to target educational activities to populations living in geographic areas that had the highest HBOC and LS burdens.

Colorado

Colorado developed a SAS software program to analyze data to determine which patients met **NCCN guidelines** for referral to genetic counseling based on risk criteria for HBOC and LS (see criteria below). Required resources included staff time to consult with clinical experts, review NCCN guidelines, develop and run the program, and analyze the data. Staff reviewed the NCCN guidelines with clinical experts periodically to ensure the program was using the most up-to-date information. The state worked with genetic counselors, and genomics and cancer registry staff at the health department to complete this effort.

Criteria for HBOC

- Breast cancer ≤50
- Two breast cancer primaries
- Breast cancer ≤60 that is triple negative for EP/PR/HER2
- Male breast cancer
- Ovarian cancer at any age (epithelial non-mucinous)
- Metastatic prostate cancer (Summary Stage 4-7)
- Ashkenazi Jewish descent with breast, ovarian, or pancreatic cancer at any age
- Breast and pancreatic cancer at any age

Criteria for Lynch syndrome

- CRC or endometrial cancer <50
- CRC or endometrial cancer at any age that is MSI unstable or MMR gene deficient
- CRC or endometrial cancer with metachronous or synchronous LS associated 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.

Since the Colorado Cancer Genomics Program is housed within the state cancer registry at the Colorado Department of Public Health and Environment, it did not have any challenges in accessing the data. Analyzing state registry data using the program helped inform Colorado's activities and approaches to educating providers and creating systems change to improve access to genetic counseling and testing. Findings were included in presentations and educational resources, such as the number of breast, ovarian, colorectal, and endometrial cancers diagnosed each year and the number expected to be associated with an inherited mutation. Data were also shared with reporting health systems to encourage systems change in referral practices through feedback interventions.

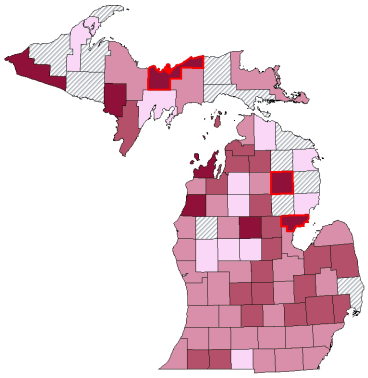
GEOGRAPHIC ANALYSIS OF CANCER REGISTRY DATA

Resources	Challenges	Outputs/Outcomes
• Staff time • GIS mapping software/capacity	• Having staff with experience or expertise in GIS analysis	• Data to identify areas of high need • Can develop targeted interventions for areas with highest need

State health departments can use cancer registry data to map out cancer cases associated with hereditary cancer syndromes such as breast, ovarian, prostate, and pancreatic cancers. These results can then be used to identify areas for targeted activities for the public, providers, and health systems. Some health departments developed maps that overlay hereditary cancer cases with additional data, such as location of health systems that offer cancer genetic services, to identify areas of high need that lack adequate genetic services. Note that the availability of telegenetics, or genetic counseling and testing delivered through telehealth services, may not be captured using these methods.

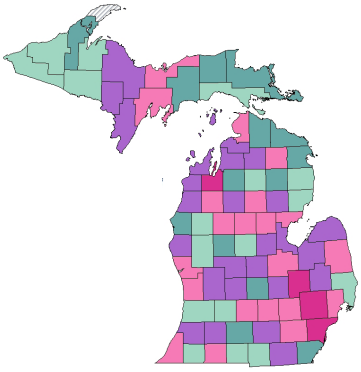
Michigan

Michigan used cancer registry data to map locations of cancer cases associated with hereditary cancer syndromes to identify the counties with the highest incidence of hereditary cancers. Michigan overlaid those maps with data on the use of genetic counseling, which the state collected through its Hereditary Cancer Network Database. Combining these maps allowed the health department to identify counties with the highest burden of cancers associated with hereditary cancer syndromes but the lowest use of genetic counseling. The resources required to create these maps included staff time, GIS mapping software and trainings for staff, and access to additional data to overlay on the maps. The mapping activities allowed Michigan to offer provider trainings at health systems where they were most needed and health communication messages to the public. In addition, Michigan developed and disseminated resources for providers and health systems across the state on how and where to refer patients for genetic services.



Map depicting the incidence of young female breast cancer (diagnosed <_50 years of age) in Michigan by county

Data source: Michigan Department of Health and Human Services, Michigan Cancer Surveillance Program, 2013-2017



Map depicting the combined incidence of select cancers associated with Hereditary Breast and Ovarian Cancer by county

Data source: Michigan Department of Health and Human Services, Michigan Cancer Surveillance Program, 2013-2017

USING THE STATE REGISTRY TO CONDUCT A SURVEY

Resources	Challenges	Outputs/Outcomes
• Staff time and expertise • Survey administration • Data processing • Human subjects review	• Significant lead time • Low response rates	• Data on barriers and facilitators of cancer genetic service use • Data on patterns of cancer genetic service use by variables of interest • Results used to inform educational activities and policy/systems change

Survey data may help programs identify barriers and disparities in access to and use of cancer genetic services, and inform the design and implementation of patient, provider, and systems resources and interventions. Following human subjects review, programs can use the contact information collected by the cancer registry to survey cancer survivors, their family members, or their reporting providers and institutions. These surveys can cover a wide array of topics, including—

- Use of genetic counseling and testing.
- Experiences with providers and health systems.
- Experiences and health services used after receiving genetic test results.
- Knowledge, attitudes, and beliefs about cancer risk and genetic testing.
- Use of direct-to-consumer genetic testing.

Policies and procedures for patient and provider contact may vary from state to state and may affect feasibility.

Oregon

Oregon used data from its cancer registry to identify cancer survivors who met NCCN referral criteria. It sent a survey to these cancer survivors and their health care providers to identify barriers to genetic counseling and testing. To get survivors' contact information from the registry, Oregon had to complete a data request, meet cancer registry program requirements, and undergo a Science Team review (similar to an institutional review board (IRB)). Surveys were also sent to the provider of record. The patient survey assessed barriers and facilitators to use of and access to cancer genetic services. Each survey mailing included an educational packet on the hereditary cancer syndrome associated with the case (HBOC or LS).

This activity required significant staff time to prepare and administer the surveys, conduct analyses, and report results. Survey costs included printing, postage (mailing and return), and incentives. Although Oregon had a low response rate (13% to 27%), respondents did increase their knowledge and awareness of hereditary cancer syndromes. These results will help Oregon develop activities to address barriers to genetic counseling and testing and focus their future outreach activities to address gaps.

USING REGISTRY DATA FOR PROVIDER EDUCATION AND SYSTEMS CHANGE

Resources	Challenges	Outputs/Outcomes
• Staff time • Contracts with relevant organizations • Funds for developing and printing resources	• Time-intensive • Partnering with health systems, clinics, and providers	• Increased provider knowledge • Improved referral rates to genetic counseling services

State health departments have used the results of their analyses on hereditary cancer burden to include localized data in provider education trainings and resources. States disseminated results and other information to providers through presentations, conferences, webinars, and print resources such as booklets and informational packets. States used data from the cancer registry to inform providers and institutions about patients who were potential candidates for genetic counseling or testing for HBOC or LS. State health departments can implement these activities with varying intensities depending on their resources. Low-intensity implementation has included using site-specific data in educational materials, while high-intensity implementation included using results to work directly with health care systems to affect provider behavior and change policies and practices on referral to cancer genetic services.

Colorado

Colorado collaborated with three urban hospitals to test using registry data to identify patients at risk for hereditary cancer syndromes, then review medical records to determine if they had been referred to genetic services. They found that only half of eligible patients overall were referred for genetic services, and only 20% of patients at increased risk for LS were referred. The health department conducted interviews and focus groups with hospital staff to assess feasibility and sustainability of the project. This was a time-intensive activity for the genetic counselors at participating hospitals, who were responsible for most of the project implementation and evaluation. One hospital used a summer intern to complete the activity and perceived the activity as less burdensome. Results of the project were a catalyst for health systems to improve hospital referral processes through policy changes and provider feedback interventions. In addition, two of the hospitals were able to use the activity as a quality improvement project to meet **Commission on Cancer accreditation requirements**.

Washington

Washington used data from the Washington State Cancer Registry and the SEER Program at the Fred Hutchinson Cancer Research Center to create The Heritable Cancer Facility Profiles for health care facilities that report cancer data to these registries. The Heritable Cancer Facility Profiles served as a learning tool for staff at these facilities to recognize at-risk populations and help connect patients with additional health resources. By raising awareness and educating health care facilities, the Profiles led to discussions within the health care facilities about policy changes that could increase the identification of people and their families with hereditary cancer syndromes.

Each site-specific facility profile was distributed to management staff such as the chief medical officer, patient care service executives, oncology clinic managers, and pathology laboratory managers. The facility profiles highlighted the number of cases at each site and included educational material and information on HBOC and LS, how at-risk people may benefit from additional genetic evaluation, and the locations and contact information of cancer genetic service providers in Washington.

LINKING CANCER REGISTRY DATA WITH OTHER DATA SOURCES

Resources	Challenges	Outputs/Outcomes
• Staff time • Data request/access to data	• Feasibility of linkages • Small numbers	• Ability to identify trends • Ability to analyze data not typically recorded in the cancer registry

Cancer registry data can be linked with other data sources to help states better understand hereditary cancer burden, use of genetic counseling and testing, and other findings that can help with program planning. States have attempted to link registry data with research databases, all-payer claims data, and other insurance company claims data. While some programs have been successful, others have encountered challenges. Some states were unable to link any registry data with claims data because of administrative and logistical barriers, while others were able to link only a small number of cases.

Utah

Utah linked its cancer registry data with the Utah Population Database (UPDB), a research database with genealogy information on Utahan families at the University of Utah. UPDB can explore familial relationships, including family history of cancer, as well as demographic and other health-related information. Utah subcontracted with UPDB and had to obtain approvals through the university IRB and a separate governing body that oversees use of the database. The cost included the subcontract and staff costs for setting up the contracts, gaining approvals, creating queries, analyzing data, and disseminating findings.

Utah didn't have any major challenges but did have to wait for approvals to access the data. Linking the family history fields to cancer registry data helped Utah identify a large pool of people who met criteria for genetic testing. These results helped the Utah Genomics Program understand the proportion of the state population eligible for genetic counseling and testing. It used this information to develop provider education materials and **a manuscript**, and to target activities to a variety of health care providers throughout the state.

ADDING OR EXPANDING DATA FIELDS COLLECTED BY THE CANCER REGISTRY

Resources	Challenges	Outputs/Outcomes
• Staff time • Data collection costs • Stakeholder buy-in	• Time-intensive • Authorization to collect additional data	• Additional data points for surveillance • Data for program planning

State health departments can work with the cancer registry to add or expand data fields they collect. New fields can provide valuable surveillance data that can be used in program planning to develop activities and interventions. New fields could include family history of cancer, referral to or use of genetic counseling, use of germline genetic testing and results, or results of biomarker tests such as microsatellite instability (MSI) or immunohistochemistry (IHC).

However, determining the feasibility of collecting new data fields is often a time-consuming process that involves working to create broad agreement on adding the new variable among health systems and cancer registrars and conducting feasibility studies on each variable. Before a new variable can be added, health systems and registrars need to ensure it can be abstracted through medical record reviews. States should weigh the added value of the new variable against the costs of data collection and the added work for registrars to collect the new variable.

Colorado

Colorado developed a series of cancer registry codes to monitor the uptake of universal testing for LS associated tumors and use of genetic counseling and testing among cancer patients in partnership with their state cancer registry and other state cancer programs, supported by additional funding received by the National Program of Cancer Registries (NPCR). New fields included MSI testing for colorectal and endometrial cancers, BRAF for colorectal cancers, Ashkenazi Jewish ancestry, referral to genetic counseling, and referral for genetic testing. The Central Colorado Cancer Registry staff assessed feasibility by developing protocols for capturing relevant data and coding by reporting facilities. NCCN guidelines were used to develop coding standards in the software. Medical record abstraction was then conducted by facility cancer registrars starting in 2018. The central registry then evaluated the quality of data submitted for these new fields by assessing completeness and representativeness. A steep learning curve was associated with developing the updated code sets to merge the new items into existing data collection and abstraction protocols. The cancer registry found that while some data were already being collected, registrars needed further training on abstraction and coding processes. Some of the biggest challenges faced in the inclusion of these new fields concerned cancer registry infrastructure, specifically accessing and updating software, access to records, and time. The development of protocols, abstraction, and evaluation of new fields was a 2-year process. BRAF for colorectal cancers was added to the standard data items collected by NPCR starting in 2021.

Utah

Utah genomics program staff, the state cancer registry, and genetic counselors from two large health care systems worked together to determine if it was feasible for health systems to report whether eligible patients received genetic services (genetic risk assessment, counseling, or testing) for HBOC. They tested the feasibility of reporting by abstracting data on family cancer history, referrals and use of genetic services, and results of testing from medical records of a random sample of eligible cases. Results indicated that although it was feasible to abstract data on family history related to HBOC, these fields were too complicated to collect consistently with low levels of error.

The registry decided to collect three variables—referral to genetic counseling, HBOC germline test performed, and HBOC test results—starting in 2019 on all male breast cancers, all in situ and invasive breast cancers in women aged 60 years and younger, and all invasive ovarian, fallopian tube, and primary peritoneal cancers. The partners worked with stakeholders across the state to define the new reportable data items, which are now mandatory reporting items across the state. The cost of the activity included genomics program staff time and a subcontract with the registry to pay staff to perform additional data abstraction and analysis.

ADDITIONAL RESOURCES

National Cancer Registries

- CDC's National Program of Cancer Registries (NPCR): www.cdc.gov/cancer/npcr/
- National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program: https://seer.cancer.gov/about/overview.html

Data Access and Use

- United States Cancer Statistics (USCS): www.cdc.gov/cancer/uscs/
- United States Cancer Statistics Public Use Databases: www.cdc.gov/cancer/uscs/public-use/
- United States Cancer Statistics Restricted Access Data: www.cdc.gov/rdc/B1DataType/Dt131.htm
- State-Specific Cancer Data Access Requirements for Research: www.cdc.gov/cancer/npcr/data_access/
- United States Cancer Statistics Data Visualizations Tool: www.cdc.gov/cancer/dataviz
- State Cancer Profiles: www.statecancerprofiles.cancer.gov/incidencerates/
- CDC WONDER: https://wonder.cdc.gov/cancer.html
- SEER*Stat data analysis software: https://seer.cancer.gov/seerstat/
- SEER*Stat tutorials: https://seer.cancer.gov/seerstat/tutorials/

Michigan Data Brief

- www.michigan.gov/documents/mdhhs/Geographic_Distribution_of_Select_Hereditary_Cancers_and_Genetic_Services_688966_7.pdf [PDF-1.1MB]

Relevant Publications

Methods

- Predictors of response outcomes for research recruitment through a central cancer registry: www.ncbi.nlm.nih.gov/pmc/articles/PMC6494669/
- Unlocking the potential of population-based cancer registries: www.ncbi.nlm.nih.gov/pmc/articles/PMC6851856/
- Using a state cancer registry to recruit young breast cancer survivors and high-risk relatives: www.ncbi.nlm.nih.gov/pmc/articles/PMC3599993/
- Recruiting families at risk for hereditary breast and ovarian cancer from a statewide cancer registry: https://pubmed.ncbi.nlm.nih.gov/28197806/
- Public health approaches and barriers to educating providers about Hereditary Breast and Ovarian Cancer syndrome: www.ncbi.nlm.nih.gov/pmc/articles/PMC4934553/

Outcomes

- Population prevalence of individuals meeting criteria for hereditary breast and ovarian cancer testing: www.ncbi.nlm.nih.gov/pmc/articles/PMC6825998/
- Disparities in genetic services utilization in a random sample of young breast cancer survivors: https://pubmed.ncbi.nlm.nih.gov/30385886/
- Use of cancer genetics services in African-American young breast cancer survivors: https://pubmed.ncbi.nlm.nih.gov/27117712/
- Improving screening uptake among breast cancer survivors and their first-degree relatives at elevated risk to breast cancer: www.ncbi.nlm.nih.gov/pmc/articles/PMC7037204/

Funded Programs (Current and Past)

- Colorado: http://cocancergenetics.org/
- Connecticut: https://portal.ct.gov/DPH/Genomics/Genomics-Home/Public-Health-Genomics
- Michigan: www.michigan.gov/mdhhs/0,5885,7-339-73971_4911_4916_47257_68337-480214--,00.html
- Oregon: www.oregon.gov/oha/PH/HEALTHYPEOPLEFAMILIES/WOMEN/HEALTHSCREENING/Pages/Genetics_Services.aspx
- Utah: https://cancerutah.org/cancers/hereditary-cancer/
- Washington: www.doh.wa.gov/ForPublicHealthandHealthcareProviders/HealthcareProfessionsandFacilities/PatientCareResources/GeneticServices/CascadeScreening