2020 NPCR WASHINGTON STATE CANCER REGISTRY SUCCESS STORY

STORY TOPIC/FOCI: Public Health Impact, Collaborative Partnerships, and Data Use

STORY CATEGORY: Public Health Impact

STORY TITLE: Mapping Selected Potential Heritable Cancer Cases by Zip Code at Diagnosis from the Cancer Registry to the Location of Cancer Regional Genetic Clinics (RGCs) in Washington State to Assess Burden and Access for Cancer Genetics

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SUMMARY

Hereditary cancer syndromes, such as hereditary breast ovarian cancer syndrome (HBOC) and Lynch syndrome (LS) are caused by genetic mutations that confer a high probability for cancer development to those who inherit the mutation. These syndromes significantly increase risk for several types of cancers among those who inherit the mutation. Additionally, these individuals are often diagnosed with cancer at younger ages than those without the syndromes. Diagnosing hereditary cancer syndromes in these individuals represents an important public health issue because of the opportunity for prevention and/or early identification and to better manage patient care. These syndromes are also largely undiagnosed – less than 2% of people with Lynch Syndrome are diagnosed, for example (Hampel, 2011). That is why the Screening and Genetics Unit (SGU) and the Washington State Cancer Registry (WSCR) at the Washington State Department of Health (DOH) collaborated and utilized WSCR data from 2017 to identify cases of (potentially) inherited cancers and overlaid the location of these cases with the location of the cancer Regional Genetic Clinics (RGC) in Washington State (WA). The criteria established by the National Comprehensive Cancer Network (NCCN) was used to identify the potential hereditary cancer syndrome cases (Daly, 2020; Gupta, 2020). To identify potentially inherited cancer cases, we used the NCCN criteria to select women with breast cancer age 50 or younger, men with breast cancer, women with ovarian cancer, any person with colon cancer age 50 or younger, and women with endometrial cancer age 50 or younger. Geocoding cases in this manner was intended to provide a more granular identification of the potential heritable cancer burden and access for cancer genetics across Washington State.

CHALLENGE

Many people with hereditary cancer syndromes are unaware of their increased risk for developing cancer because they have not yet been diagnosed with the syndrome. Before this project, SGU and RGCs in Washington State could not identify one of the factors influencing the low proportion of diagnoses among cancer patients with hereditary cancers was lack of access to genetic services. While the demand for genetic services is increasing in part due to the lowering costs of genetic testing, advances in science and healthcare, and the growing use of direct-to-consumer genetic testing, access to trained genetic counselors have not kept pace with the demand. SGU previously investigated the demand for genetic services and found that

wait times for appointments nearly doubled on average between 2013 and 2017 (unpublished data).

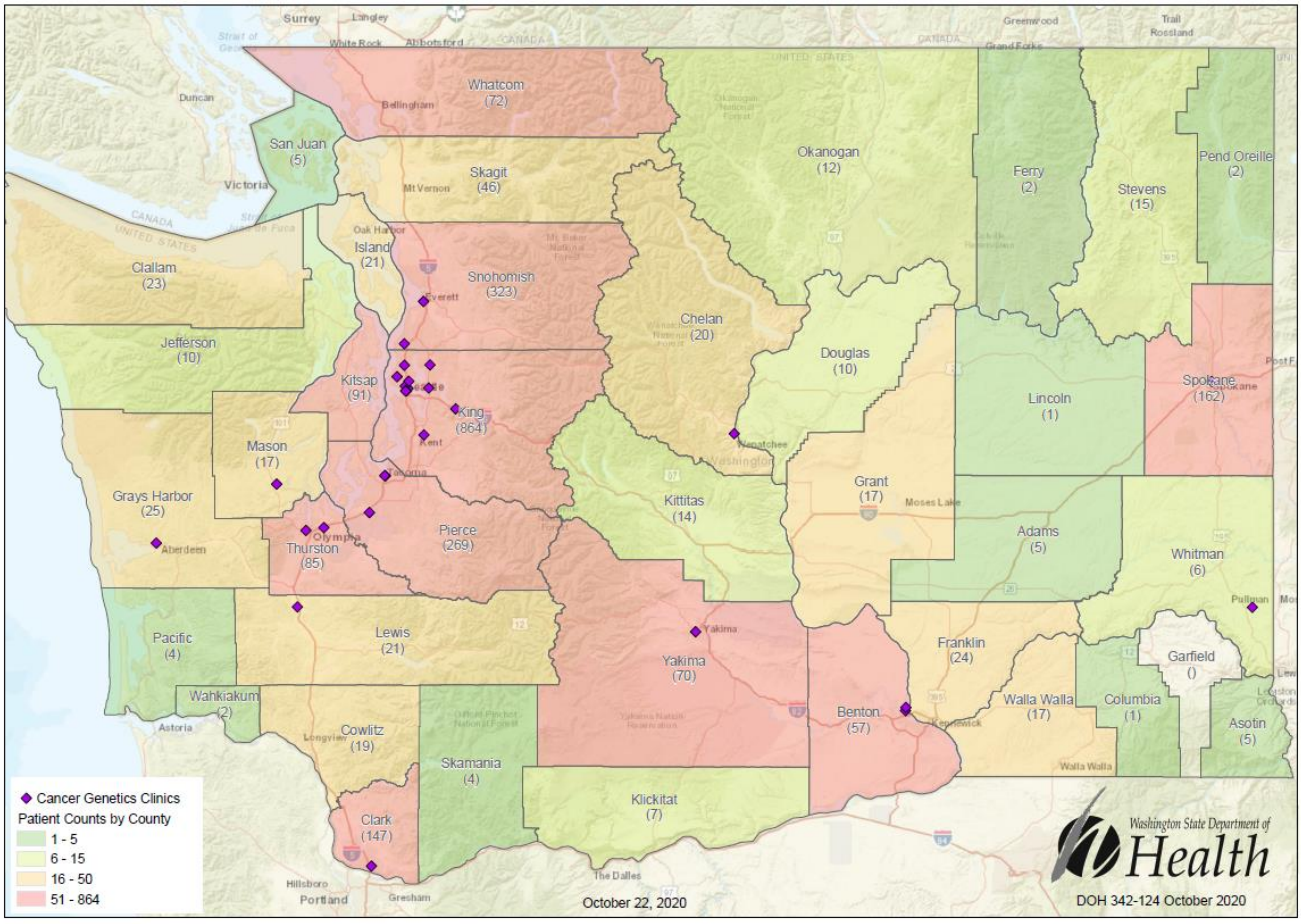
SOLUTION

Potential hereditary cancer syndrome cases were identified using the criteria established by the National Comprehensive Cancer Network. Cancer genetic clinics in WA were identified and their locations mapped. The locations of these potential cases were mapped in relation to cancer RGC locations to better understand the overlap of access to burden and identify if there are gaps in access in areas of high burden. This map was created for and disseminated to stakeholder across the state, including genetics providers and cancer RGCs – to collect feedback on the identified gaps. Additionally, SGU is seeking feedback from all genetic providers on their use of telehealth. This feedback should provide some clarity as to whether patients in certain areas are being served. A major focus going forward will be to work with RGCs to improve provision of service in the northern Puget Sound area, especially Whatcom County, where the mapping shows high frequencies of potential hereditary cancer syndrome cases yet lacking in cancer RGC locations in the area.

RESULTS

The WSCR provided the potential hereditary cancer cases with the zip code at diagnosis and reporting facility information. There were 2, 495 cases that met the NCCN criteria. The SGU had the address and location of all cancer genetic clinics in Washington State. There were total of 28 cancer RGCs in WA. The cancer registry data was aggregated and mapped by zip code with the location of the cancer RGC. When DOH policies on data suppression for case counts under 10 were applied to the zip code map, much of the granularity was lost, and the distribution of cancer cases appeared clustered. To better visualize the distribution of cases, we then mapped cases by county along with the cancer RGC locations. Below is the map that shows cancer genetic clinic locations and potential hereditary cancer cases in Washington State by county. The map showed that cases were distributed across most all counties. Of the 39 counties in WA, 38 counties had at least one case. Cases were highest in the more populous counties of the northern Puget Sound area (King, Pierce and Snohomish counties). It also provided a quick visual highlighting where the demand for cancer genetic services may not be met either due to the lack of nearby clinics or the amount of potential cases in the area.

Cancer Genetic Clinic Locations and Hereditary Cancer Case Burden by County in Washington State



SUSTAINING SUCCESS

WSCR plans to provide recent diagnosis year data once it is available and the SGU can update the map every year with the new diagnosis year data. We are hoping that ongoing work of this nature will lead to policies for telehealth that help in reducing the gaps in access to genetic services. We are also planning to add demographic information on the map such as age groups, race and ethnicity.

This collaboration has also helped to initiate active surveillance for HBOC and LS and increase provider awareness regarding clinical guidelines for genetic testing in patients at risk for HBOC or LS. We will identify all potential HBOC and LS cases from people whose cancer is diagnosed and reported to Washington State Cancer Registry (WSCR). We will also notify reporting healthcare providers about potential risk for the patients and where to refer their patients.

REGISTRY CONTACT INFORMATION

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Sources

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