CANCER PREVENTION & RESEARCH INSTITUTE OF TEXAS

Award ID:
PP140182

Project Title:
Population Based Screening for Hereditary Breast and Ovarian Cancer Syndrome and the Lynch syndrome in the Underserved

Award Mechanism:
Competitive Continuation/Expansion - Evidence-Based Cancer Prevention Services

Principal Investigator:
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Entity:
The University of Texas Southwestern Medical Center

Lay Summary:

Hereditary Breast-Ovarian Cancer (HBOC) and Lynch syndrome (LS) are among the most common inherited cancer predisposition syndromes. For those carrying these mutations, the lifetime risk for breast, ovarian, colorectal and endometrial cancer is as high as 85%. An estimated 72,280 Texas residents can be expected to be mutation carriers based on the frequency of mutated genes. Identifying individuals at high risk for cancer because of germline mutations in major cancer predisposition genes has become a far-reaching public health issue, representing a distinct opportunity to reduce cancer incidence and the resulting burden of a cancer diagnosis. Access to genetic services in the uninsured, ethnic/racial minorities or geographically isolated is often non-existent, resulting in those at high risk to go unidentified and unmanaged.

With CPRIT support, the initial Cancer Genetic Services for Rural and Underserved Populations in Texas (Genetics 1) program has successfully provided comprehensive genetic screening and testing with follow-up services to large safety-net populations across Dallas and Fort Worth, in addition to implementing telemedicine sites in four rural and underserved counties. In 20 months, the Genetics 1 program achieved exemplary results with more than 61,000 women screened for HBOC risk using the Family History of Cancer (FHOC) tool, discovering 22 mutation carriers. Tumor analysis for LS identified 37 Lynch probands, a four-fold increase in case identification. The web-application for CancerGene Connect was enhanced, establishing seamless throughput by providing an online interface for patients to enter risk information prior to the counseling session. This program improves appointment efficiency while drastically reducing genetic consultation time. The FHOC tool is now embedded into mammogram processes enabling more than 20,000 patients annually to complete a 60-second questionnaire at time of mammogram. Automation identifies only those estimated at increased genetic risk and has boosted efficiencies. In safety-net programs, 54 mutation carriers have been identified representing a 125% increase in mutations and a patient volume increase of 355%. At four telemedicine sites, 115 patients received genetic services, exceeding the goal by 187%. While the effectiveness of population screening is well documented, analysis of follow-up data has only just been made possible with a new modeling program. The program evaluates mutation detection rate, compliance, and prophylactic surgery uptake to project its impact on the overall cancer incidence in high risk patients.

Despite these successes, a critical disparity in adherence to medical management guidelines was identified between underserved and insured populations. Using the insured population as a baseline, the comparison indicates what is achievable for uninsured and underinsured given the appropriate resources, while highlighting the need for focused physician and patient education interventions to impact this prominent barrier. As such, formal CME education programs and conferences along with other resources using website education, videos, print and e-mail links will address compliance with management guidelines for clinicians and patients. To leverage partnerships in rural communities and improve program reach into areas without genetic services, the new program will partner with Moncrief Cancer Institute's breast screening program, expanding services to 15 additional rural counties. More than 3,600 women will be screened for HBOC genetic risk annually through the rural expansion by embedding the FHOC screening tool into the Moncrief mammogram registration process. The program will also pilot Telephone Genetic Counseling (TGC) to increase accessibility of services while decreasing patient transportation costs, inconvenience and missed work, addressing barriers to care and increasing appointment adherence, in rural underserved populations.

Implementation of automated FHOC screening tools into mammogram registration processes in Dallas and Fort Worth will allow over 85,000 women over three years to complete the tool identifying those who may be at increased genetic risk. Patient education interventions embedded in CancerGene Connect and those provided to clinicians will address compliance strategies to promote adherence to current evidence-based guidelines. Genetic Navigation will be streamlined using a navigation dashboard to direct efforts to impact surveillance of known mutation carriers. While numerically, the project will impact a small number of individuals, because of the extremely high risk of cancer in this group, the individual impact will be enormous. Comprehensive case identification through expansion into rural areas confirms program portability with potential to impact an estimated 72,280 Hereditary Breast and Ovarian cancer or Lynch Syndrome mutation carriers in Texas.