Primary Care Genetic Testing – Getting Genetic Testing to the Public

Preventing cancer deaths through primary prevention activities is understudied. One prevention strategy is to engage patients in genetic testing to better enable risk stratification, target cancer prevention and surveillance, impact healthcare, and save lives.

Unfortunately, due to barriers at several levels, genetic risk is often not identified until after a cancer diagnosis. Provider barriers include inadequacies in recognizing hereditary risk, challenges in making patient referrals, and availability of genetic professionals to provide in-depth counseling. Patient barriers include lack of knowledge of testing, financial costs, and inadequate access to genetic testing services.

While implementation studies have been conducted in urban facilities with high resource levels under optimal conditions, few have been conducted in the clinic or system level. This University of Washington Medical Center study will compare the processes and outcomes of two methods of screening, offering testing, and evaluating follow-up care at twelve urban and rural clinics.

The EDGE study (Early Detection of Genetic Risk) is testing a comprehensive hereditary cancer screening program, using a population-level approach in the primary care setting over a two-year period. The program involves collecting personal and familial cancer history, assessing an individual's risk of hereditary cancers, providing genetic testing to those found at high risk, and assisting primary care providers in developing and implementing a guideline-based follow-up plan.

Twelve primary care clinics from a mix of urban and rural sites that are part of either Billings Clinic in Montana or the MultiCare Health System in Seattle, Washington will be randomized to one of two arms. Two strategies will be employed to identify and test high-risk individuals within each clinic. In the Point of Care arm, only patients who come to the primary care clinic for a visit will be invited to complete a risk assessment questionnaire detailing family history on a tablet in the waiting room to see if they are high risk and qualify for genetic testing. In the Direct to Patient Engagement arm, primary care patients will receive a letter and email introducing the study and inviting them to complete the same risk questionnaire on the study website. Patients identified as high-risk for eight of the most common hereditary cancers will be invited and given instructions for online genetic testing with Color Genomics at no cost to them and will have access to free genetic counseling.

Purpose
The goals of this study are to help patients by identifying modifiable cancer risks through genetic testing, and to determine which risk screening method is most effective at increasing the identification of genetic risk for certain hereditary cancers: tablet screening in the waiting room or by letter/email sent to the primary care clinic patient population. Ultimately, the goal is to determine feasible strategies to provide eligible patients genetic testing without increasing burden on primary care providers to fully assess family history, arrange testing and develop a guideline-based follow-up plan.

This study has been approved by the University of Washington IRB. Funding is provided by the National Institutes of Health (NIH), Grant Office ID: A140201, Funding Source ID: 1U01CA232795-01A1.

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For more information about the EDGE study, go to: https://sites.uw.edu/edgestudy/