

## Public Health Genomics Surveillance: Using Alternative Data Sources

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**Background and objectives:** An important goal of the Utah Department of Health Chronic Disease Genomics Program (CDGP) is to integrate genomics information into existing data collection systems. Recognizing the impact genomics may have on chronic disease prevention, the CDGP worked closely with several UDOH programs to develop a diverse surveillance system, taking advantage of data sources not typically used by genetic researchers. While the Behavioral Risk Factor Surveillance System (BRFSS) is typically used, not all public health practitioners have the ability to include genomics and family health history questions on it. Thus, additional data sources are needed to fully understand the impact genomics has on population health. Data sources that were explored by the CDGP include the Youth Risk Behavior Survey (YRBS), Utah Cancer Control Program's (UCCP) enrollment forms and Women's Health Survey, Youth Diabetes Registry, and Utah Population Database (UPDB).

The objectives of this session are to 1) Identify alternative data and surveillance sources available to public health professionals and 2) Present results from five alternative data sources that successfully utilized genomics information.

### Methods:

YRBS: The YRBS comprises national, state, and local school-based surveys of 9-12 grade students and is designed to monitor health risk behaviors among youth in the US. The YRBS is conducted every two years. In collaboration with the Tobacco Prevention and Control Program, the CDGP developed four genomics questions for inclusion on the 2005 and 2007 YRBS. The questions were designed to estimate the level of awareness among Utah youth regarding risk of disease based on a family history, intention of behavior change, and interest in learning more about personal health family history.

UCCP: An analysis of the UCCP's database was conducted by the CDGP. It was established that the UCCP collected family history information on breast and colorectal cancer from women who enroll in UCCP services throughout the state but had never analyzed the data. The breast cancer data was analyzed to determine the number of affected relatives of the enrollees with cancer. In addition, the UCCP solicited input from the CDGP on the development of family history of colorectal and ovarian cancer questions for the Women's Health Survey.

Youth Diabetes Registry: The registry was used to assess the incidence and prevalence of Type 1 and Type 2 diabetes in Utah children. Information for the registry is extracted from chart reviews. Data collected for the registry includes information extracted from charts of 174 pediatric patients seen at Utah clinics in 2003.

UPDB: The UPDB contains genealogical information on over 1.6 million individuals, Utah birth and death, cancer registry, and driver license records. The UPDB has traditionally been used only for research; however, the CDGP wanted to explore the potential applications of the database in determining population relative risk estimates based on family history. The CDGP formed a strong academic-practice relationship with genetic epidemiologists and researchers at the University of Utah and conducted an analysis of colorectal cancer data available in the UPDB.

### Results:

YRBS: The 2005 YRBS showed that 83% of students reported that if one of their family members had a disease that they would be at an increased risk of developing the disease; 82% reported that if a disease ran in their family that they would change their lifestyle behaviors to decrease their chance of getting the disease; and 59% were interested in learning more about their personal health family history. Results from the 2007 YRBS are currently being analyzed.

UCCP: Nearly half of the breast cancer cases reported by UCCP indicated a positive family history, showing a strong relationship between disease development and family history. When examining familial relationships of breast cancer, higher risk ratios were found among those with first-degree relatives with cancer when compared to second-degree relatives. However, the UCCP population can not be considered representative of the Utah population as many of the enrolled women in the UCCP have a lower socio-economic-status and are more likely to be a minority than the general Utah population. According to Women's Health Survey, women are more likely to get screened for cancer if they have a family history of cancer as compared to not having a family history.

Youth Diabetes Registry: Data collected showed that nearly three-fourth of the pediatric patients had a family history of diabetes. Future analyses of registry data will be conducted to determine correlation between maternal and paternal diabetes and the development of childhood diabetes and gestational diabetes.

UPDB: Colorectal cancer was selected as the first disease of interest because of its well-defined familial relationships and established public health screening guidelines. Pedigree analysis was conducted to determine the genetic disease load for the state for those at risk for development of colon cancer due to family history. Of the 10,112 patients with diagnosis of colorectal cancer before age 40, the relative risk for first-degree relatives was 3.85. Discussions are underway to use the UPDB for other chronic disease programs.

**Discussion/Conclusion:** The CDGP identified alternative data collection sources available for use in public health genomics surveillance. Strong relationships were formed with chronic disease programs and academia that allowed for successful integration of genomics and family health history into these sources. Results are providing guidance in development of educational materials, targeting interventions to those at highest risk, and future areas of research. Even though the CDGP does not practice direct control over these data sources, they provide population-based data and allow for a more diversified genomics surveillance system.