

Community Feedback on Potential Uses of Genetic Information to Predict, Treat, and Prevent Asthma

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Purpose

The Center for Genomics and Public Health (CGPH) at the University of Washington, funded by the Center for Disease Control and Prevention (CDC), conducted a consultation project in asthma and genetics to explore how genetic information and the outcomes of current asthma research may be used in the future as tools to diagnose, prevent, or improve care for people with asthma. The project provided feedback from a wide range of experts in the field of asthma, including researchers, physicians, public health professionals and community members, to determine their thoughts on how genetics may aid in future asthma care. The community component of the asthma project used a community-based, participatory research model to collaborate with established community organizations that are familiar with asthma to gain feedback from their members about the potential uses of genomics in the field of asthma. The findings from their candid responses were recorded into a final report, which is being used by the CDC to inform public health officials about directions for further research and policy development in asthma and genetics. The group at the CGPH chose to get feedback from individuals before these new technologies are implemented; instead of after they are in place, as most feedback occurs. The CGPH hopes that input from community members could be used to drive policy and let their funders know what is important to the population.



Activities Included:

- Participating in the development and implementation of a public consultation process regarding the implications of genomic research for public health efforts in asthma prevention.
- Identifying asthma advocacy organizations in Seattle representing diverse community interests.
- Contacting organizations to explore their priorities in asthma prevention and treatment and their interest in participating in a consultation process related to asthma and genomics.
- Developing a script with fictional scenarios of potential uses of genomic information in asthma prevention.
- Participating in discussions of these scenarios with representatives of advocacy organizations to identify potential goals and concerns of communities or individuals related to the use of genomic information in asthma prediction, treatment and prevention.

Timeline and Activities

	8/15-8/31	9/15-9/30	9/16-9/30	10/1-10/15	10/1-10/31
Develop Script	x	x			
Gain IRB Approval	x	x			
Identify Participants		x			
Recruit Participants		x	x		
Translate Script			x		
Advertise Meetings			x	x	
Hold Consultations			x	x	
Summarize Findings					x

Participating Organizations

Washington State PTA
 American Lung Association of Washington
 Odessa Brown Children's Clinic
 Public Health-Seattle and King County
 King County Asthma Foundation
 Healthy Homes II-Asthma
 White Center Neighborhood Asthma Community*
 South Park Neighborhood Asthma Community*
 American Lung Association*

**hosted an asthma consultation*

Feedback from Asthma Consultations

Concerns of using genetic information included:

- Potential labeling, although some saw this as an existing problem and felt that labeling may become less of a problem as discussion about asthma become more open and common-place. In the same light, it was thought that the likelihood of stigmatization associated with genetic testing will become minimal as testing becomes more common.
- When discussing the research case study, participants expressed concerns about the government, or any single entity, having information about a population (rather than doing studies in small groups of individuals). One individual expressed distrust of a population-based study, regardless of collection of genetic information.
- Overall, individuals thought that, given proper regulations pertaining to privacy and "consumer" choice, genetic testing to guide therapy would be beneficial. Although privacy and confidentiality concerns exist, some thought that the potential benefits in using genetics information to treat or diagnose asthma might outweigh the risks.
- There were mixed feelings about uses of genetic tests and about how much information people want to have about asthma genetics. One person felt the community would be more accepting of new technology if they learned about it as it developed. Other participants did not want to know about asthma genetics until it had a useful application.