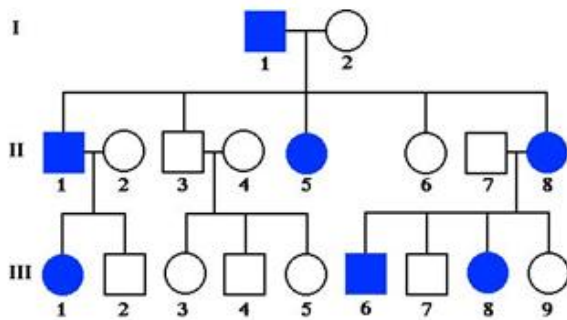


Identifying barriers to disseminating genetic research results to Latinos

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Family history information, often depicted in a pedigree (top), can provide useful information regarding current and future health risks for family members across generations (bottom).

Image provided by Ms. Rachel Malen

Increasingly, researchers working in community settings are seeking to engage the group they are working with in the research process. These efforts not only help to translate the research into practice, but also show reciprocity with study participants by involving them in the research process. Such community-based participatory research is common for work with underserved populations, and for research addressing health disparities and other social problems. One important aspect of these research methods is seeking to understand the traditions and needs of the target community, so that research results can be disseminated in ways that are respectful, understandable, and beneficial to study participants. A first step for any research program, then, is beginning a dialogue with the target population so as to identify potential barriers and opportunities. In a recent report in the *Journal of Community Genetics*, Ms. Rachel Malen and Dr. Beti Thompson in the Public Health Sciences Division describe the results of a pilot study in which

they interviewed Mexican-Americans living in rural Washington. These interviews yielded insights into how this population perceives family health history, genetics, and disease risk.

One area of rapidly growing interest is examining whether family history and genetic ancestry can partly explain observed health disparities for various diseases. One such project is the Partnership for Understanding and Eliminating Disparate Outcomes (PUEDO) for Latinas, a transdisciplinary Center for Population Health and Health Disparities (CPHHD) at the Fred Hutch. One of the goals of PUEDO is to examine the association of ancestral genetic background with breast cancer tumor biology and metabolic response to diet. As this research requires discussing family health history and genetic information, the investigators felt it was important to first identify how this potentially sensitive information is understood and perceived by study participants and their communities.

At the same time, the researchers also hoped to eventually be able to return their findings back to research participants, as well as to other Latinos around the state. Said lead author Ms. Malen, "dissemination of research results to participants is becoming more and more common, but we were unsure how our Hispanic participants would receive them, especially any genetic findings. Limited research has been done in this area. Our goal was to gauge the basic understandings of family health history, genetics, and disease risk and how these concepts interact."

To do so, the investigators worked with culturally-matched community health workers (promotores) to conduct pilot interviews among Spanish speaking Mexican-Americans living in rural agricultural communities in the lower Yakima Valley in Washington State. Key themes identified from these interviews could be grouped into three major content areas, which provided useful insights into how family health history, genetics, and disease risk were perceived by these participants. While participants were familiar with the concept of family health history and its relationship with disease risk, family discussions did not usually contain the type of specific information (age at onset, etc.) that would be important for clinical and public health applications.

Participants expressed great interest in receiving genetic information about future risk of disease, as well as a strong desire for any health information that could help them live healthier lives. Genetic literacy in this group was low, however, emphasizing the need for careful communication of results so that they are not misinterpreted or overhyped. At the same time, genetic factors did not seem of great relevance to participants' views of health or disease, and participants did not connect an increased risk of disease from family history to the concepts of biological inheritance or genetics. Identifying such gaps in genetic knowledge and perceived relevance is the first step to addressing and overcoming these potential barriers, which will be necessary for effectively translating research results into interventions that can help reduce health disparities.

Overall, the results of these pilot interviews highlight the importance of understanding the target audience before beginning the dissemination of research findings. Said senior author Dr. Thompson, "this study helps us understand how Hispanics think heredity, health and genetics are related. This is important information for this underserved population." Moving forward, the authors plan to go back to former participants and Latino community members to continue the dialogue around this line of research. Said Dr. Thompson, "this work also launched a larger study examining the dissemination of research results to Hispanic women."

Other Fred Hutch investigators contributing to this project were Ms. Sarah Knerr and Dr. Malia Fullerton.

Citation:

[Malen R, Knerr S, Delgado F, Fullerton SM, Thompson B](#). 2015. Rural Mexican-Americans' perceptions of family health history, genetics, and disease risk: implications for disparities-focused research dissemination. *J Community Genet*. doi: 10.1007/s12687-015-0245-1 [Epub ahead of print]

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