

INTRODUCTION

The *Healthy Choices through Family Health History Awareness Tool* was specific to the Institute for Cultural Partnerships' Harrisburg, PA, community of largely African Americans and Latinos. After completing the *Healthy Choices through Family Health History Awareness* project, Genetic Alliance partnered with a diverse group of eight organizations through another HRSA cooperative agreement (U33 MC06836). The Community Centered Family Health History (CCFHH) Project aimed to create customized family health history tools for each community. Those partners include:

- Alpha-1 Foundation
- Institute for Cultural Partnerships
- Intermountain Healthcare
- Iona College
- National Council of La Raza
- National Psoriasis Foundation
- Office of Justice and Peace/St. Mary's Health Wagon
- Seattle Indian Health Board's Urban Indian Health Institute

In addition to these community partners, American Society of Human Genetics and American Folklife Center advised during the materials-development phase.

The product of CCFHH is the *Does It Run In the Family?* toolkit, a set of two booklets and supplemental materials. *Does It Run In the Family?* contains some content that is static across communities; a gene is always a gene, in Harrisburg, as well as Oakland, Salt Lake City, and New Rochelle, NY. However, the personal health stories, photographs, and specific health conditions presented in each partner's customized version of the toolkit are particular to that community. All eight community partners reviewed the template and helped with the adaptation of the *Healthy Choices through Family Health History Awareness Tool*. "A Guide to Family Health History" explains the importance of family health history and how to collect it, and "A Guide for Understanding Genetics and Health" explains basic genetics concepts and introduces readers to various conditions that can run in families. All partners' customized booklets are available for download on Genetic Alliance's website, www.geneticalliance.org/ccfhh. The toolkit was not designed to replace medical model tools, but as a complementary resource to be used in combination with them.

Like its *Healthy Choices* predecessor, *Does It Run In the Family?* combines family health history, personal health stories, and genetics to help individuals and families gather their health history and use that information to make positive health choices. The key difference is its customizable nature. A tool created for a specific community in Harrisburg, PA, could not simply be reproduced and distributed to communities across the country with the expectation of positive health outcomes based on its use. Instead, we hypothesized that accessible tools produced **by the community, for the community**, would promote conversations about health within the family and translate knowledge of family health history into healthy choices.

Our diverse partner organizations reflect this belief. During the first year of this project, we engaged three racial/ethnic communities (African American, Hispanic, and American Indian/Alaska Native), one large multistate healthcare system, and two virtual communities (genetic condition-specific communities); these are considered Year 1 Partners. At the 18-month mark, we added two more communities—one rural, faith-based Appalachian community and one community and college collaboration project on aging (Year 2 Partners). At the 22-month mark, after a competitive application process, 10 more communities were awarded funding (Year 3 Partners or CCFHH Program Awardees).

We maintained five project tenets for this national, yet community-based, endeavor: accessibility, community input, sustainability, evaluation, and resource sharing. At the outset, to guide the project according to this maxim, we established basic definitions and laid out key principles for community engagement.