Ethnic groups fear of personal genomics could hurt disenfranchised communities

A decade ago, biologist Ting Wu saw a need to promote education and interest in genetics among consumers, as well as to help scientists understand how the public views their research. Recently, the Personal Genetics Education Project — known as pgEd — expanded its reach through an effort called Map-Ed that lets people take short genetics quizzes and locate themselves on a world map.

Are there certain perceptions or misperceptions you encounter regularly as you interact with the public?

Different segments of society have different levels of comfort with genetics. I think those parts of society that are very well off, that haven't experienced destitution or the fear of having something done to them medically they don't understand, may give scientists a much more optimistic attitude. [With people] who have experienced going to a hospital and having things done that they don't understand, or because of their culture or race or background come from a family lineage that has suffered, there's reticence in jumping into this new era. There are segments of society that are much less willing to become participants in some exploratory genetic project because they are—rightfully so—wary about what's going to happen with that information. Maybe scientists don't have as much interaction with that community as we should; we may not hear them as well.

What ramifications could that have for disenfranchised communities?

The part that is concerning is that there is genetic information coming out that is specific for certain ethnic groups [which] may inform how they want to lead their lives. But that requires that those individuals be willing to hear about this information and participate in studies so that their ethnic group can be better understood. Those ethnic groups that hold back and do not want to participate, for perfectly understandable reasons, will have less of a chance of benefiting medically.

The GLP aggregated and excerpted this blog/article to reflect the diversity of news, opinion and analysis. Read full, original post: No Longer Rocket Science: Helping Consumers Understand Genetic Info