

Policy and law key to ensure health equity in precision medicine

Genomics has a diversity problem. Despite the dazzling promise of genetically-tailored treatments and therapies, fundamental questions remain about whether precision medicine will advance health equity or make disparities worse. On November 29, 2018, a national conference and webcast at Meharry Medical College in Nashville will be the first to focus on the role law and policy must play to ensure precision medicine increases health equity and access.

Despite the increasing diversity of the US, the research driving precision medicine has been based on a population that is overwhelmingly white and European in ancestry. This has serious scientific implications. As Vence Bonham, Jr., of the National Institutes of Health (NIH) has written in a JAMA article he co-authored, "Gaining complete insights about the relative roles of genomic variation, social context, and physical environment in human traits, health, and disease requires greater participation of individuals with ancestors from all regions of the world." What is keeping more people from research participation? Among their worries may be surrendering sensitive health information for inclusion in large databases, as well as fear of privacy breaches, data misuse, and discrimination. All of these concerns require careful consideration of whether law and policy provide adequate protection for patients and research participants.

The Nov. 29 event will also examine the obstacles currently blocking the widespread adoption of genomic medicine, and ask what legal and policy approaches will maximize access to it in the future. For example, what laws and policies will guarantee that insurance or social safety-net programs cover the cost of genomic analysis and access to the individualized care that precision medicine offers? Ensuring such access is of particular importance for economically disadvantaged people, including those who lack insurance or are under-insured.

Meharry-Vanderbilt Alliance Executive Director Consuelo H. Wilkins, MD, MSCI, a featured speaker at the conference who is spearheading participant engagement efforts for the federal All of Us precision medicine program, is renowned for her work getting racial and ethnic minorities involved in research. She notes, "Precision medicine looks beyond people as members of a group to consider them as individuals. If we're really serious about addressing health disparities, we need to build an inclusive process that considers biology, genetics, culture and environment when developing tailored therapies and putting them into clinical practice."

This conference and webcast is sponsored by the Meharry-Vanderbilt Alliance; Vanderbilt University Medical Center; the University of Minnesota's Consortium on Law and Values in Health, Environment & the Life Sciences; and the Minnesota Precision Medicine Collaborative. It is part of the National Institutes of Health-funded LawSeqSM project, which is dedicated to building

a sound legal foundation for translating genomics into clinical application.

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