Making Genomics as Diverse as Humanit y

By Robert C. Green

Medical research has had its share of problems. It sometimes proceeds without much thought about the communities it affects. It can produce a wealth of new knowledge, but too often those discoveries are for the benefit of a narrow group of people. It can serve as a venue for meeting the needs of those in society who most need it, but just as often it leaves many behind.

We are now on the edge of a new era of medical research, one that promises to treat the root cause of some of our most urgent health challenges. And yet only 7% of clinical trials involve people of color. The National Institutes of Health (NIH) have committed to increase the diversity of their clinical trials to 50% by 2021, a laudable goal. But how do we ensure that this reflects our reality?

With clinical genomics, there is again the potential for greater diversity than ever before. In the past, the promise of individuating treatments for some illnesses was not so much about treating patients, but instead about identifying subgroups of people that had similar characteristics. These subgroups were identified in way that was not necessarily representative of the population at large.

In our era of big data, however, the promise of weighting genomics on the same data to treat individuals. But can this be done fairly? What if there are differences in how people of different backgrounds are represented in these databases? What if some groups are underrepresented?

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Medical genetics is the study of genes and variations that affect human health. It involves understanding the relationship between genetic variation and disease.