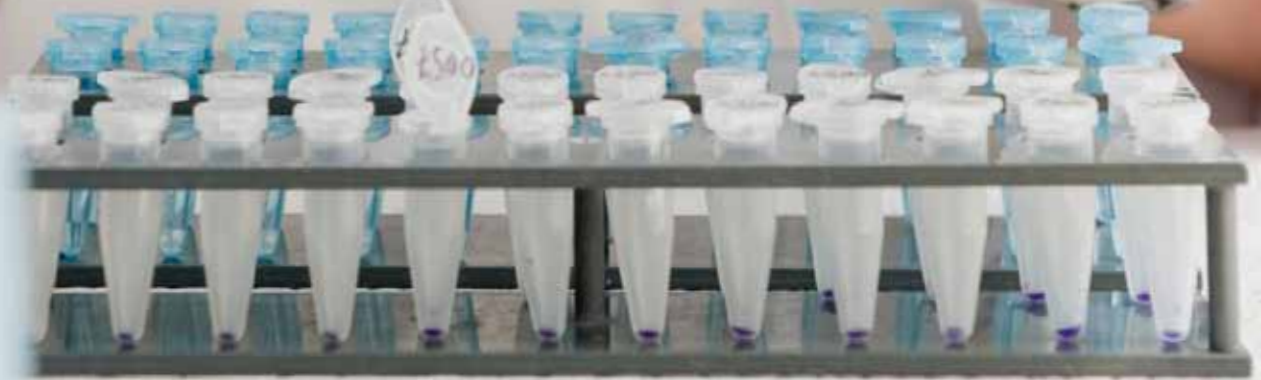


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# Addressing Race and Genetics

Health Disparities in the Age of Personalized Medicine

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# Introduction and summary

The human genome sequence has been fully completed for a decade now and the price of full genome sequencing is dropping precipitously. Many believe that with these developments, a new era of personalized medicine is about to hit full speed. Personalized medicine is essentially “the use of genetic susceptibility or pharmacogenetic testing to tailor an individual’s preventive care or drug therapy,” although some definitions also include the development of patient outcomes research, health information technology, and care delivery models.<sup>1</sup> Put more simply, it means the development of medicines and therapies tailored to patients’ unique genetic traits and risks.

The field is evolving rapidly but many hurdles still remain. Individually tailored drugs based on a patient’s genetic makeup are far off, and the cost of developing drugs for genetic subpopulations with largely similar genetic traits for one or more diseases hinders developments in this arena. Similarly, the lack of standards surrounding direct-to-consumer genetic tests and the lack of robust, large-scale genomic data for many diseases and conditions are additional hurdles.

Nevertheless, personalized medicine is making its way into the mainstream. Estimates by PricewaterhouseCoopers indicate that the market for personalized medicine, currently a \$232 billion industry, will grow at a rate of 11 percent annually.<sup>2</sup> Personalized medicine is also making serious strides in the pharmaceutical industry with drugs like the colon cancer drug Erbitux, which is most effective in patients with a certain genetic mutation.

Personalized medicine also has the potential to rein in rising health care costs. For instance, physicians can better prevent adverse drug reactions by using genetic information to calibrate the ideal dosage of the blood-thinning drug Warfarin for an individual patient. This alone could prevent 85,000 serious bleeding cases and 17,000 strokes, and save the health care system \$1.1 billion annually.<sup>3</sup>

But the health care and scientific communities will still have to answer important questions about who will have access to these new medical advancements as they develop. Health disparities persist between different groups for various reasons including access to care, lifestyle factors, socioeconomic status, and genetics. Studies indicate that minorities have less access to health care and generally receive a lower quality of care. Studies show that African Americans have lower incidence of breast cancer than white women, for example, but suffer greater mortality.<sup>4</sup> Heart disease is widespread among minorities and a leading killer in the African-American community.

Personalized medicine can potentially alleviate these discrepancies since it could allow physicians to prescribe medication that treats the disease more effectively. African-American women suffer from a more aggressive form of breast cancer that tends to be estrogen resistant, for example.<sup>5</sup> Profiling the genes of the tumor and the genes of the patient could allow a doctor to prescribe the most effective drug regimen.

Yet certain issues regarding racial and ethnic health disparities need to be addressed in order for personalized medicine to offer the greatest benefit to all. This paper examines these issues in detail and then offers some ethical guidelines for policymakers to consider, among them:

- There must be a frank discussion of the social and methodological appropriateness of using race or ethnicity as disease proxies.
- Genetic variation research and clinical trials must systematically incorporate such discussions into their individual study designs and the research itself.
- We cannot ignore structural inequalities in access to health care and in fact should seek to reduce them through research that looks at social, environmental, and behavioral contributions to health status as well as research on the outcomes of different care delivery models for different populations.

In the pages that follow we will demonstrate why these proposed ethical guidelines are essential to the development of personalized medicine in our country.

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