

Personalized genomic medicine: How much can it really empower patients?

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Personalized genomic medicine is hailed as a revolution that will empower patients to take control of their own health care, but it could end up taking control away from patients and limiting their treatment choices, concludes an article in the [Hastings Center Report](#). A [commentary](#) responding to the article, by the editorial director of Health and Family at Consumer Reports, also appears in the journal.

Genomic science provides two categories of data, the authors write: pharmacogenomic information and genomic susceptibility information. Pharmacogenomic information forecasts how an individual might respond to a particular therapy. Genomic susceptibility testing predicts a patient's chances of warding off or succumbing to an environmental threat or disease.

Genomic [medicine](#)'s stakeholders – including direct-to-consumer genetic testing companies, private research centers, and the National Institutes of Health – are deeply invested in promoting how this information will benefit [patients](#). The authors call this "empowerment rhetoric." And yet the added knowledge that comes from both pharmacogenomic information and genomic susceptibility information could have a negative impact on how much power a patient really has.

The results gleaned from pharmacogenomic information could pressure patients to comply with physicians' recommendations, the authors suggest, because molecular profiling would allow doctors to give orders with more authority. "In fact, because [genomic medicine](#) generates more

risk information and makes that information the key lens for approaching health and disease, patients may actually find that they have less ability to influence health care decisions and treatments," the authors state.

The virtues of genomic susceptibility information could also go awry. First, because disease prevention relies heavily on lifestyle changes, responsibility is shifted from doctor to patient. Patients who don't make the "right" choices could be deemed irresponsible, the article says. Second, genomic information can for the time being only reveal the health risks of groups of people. Rather than provide individualized assessments, it classifies people into "genetic superfamilies." The authors argue that "population classification schemes based on racial and ethnic categories can be actively disempowering for individuals, by encouraging potentially prejudicial associations between their group affiliations and health care risks."

Patient empowerment is marketed as a paradigm shift because it puts medical data in the hands of the consumer, not just the doctor. But the authors conclude that the focus on empowerment could clash with the reality of what patients are willing or able to do with the information they receive. "The idea of patient empowerment may run up against not only the limits of patients' control over their health, but also the limits of patient control over health care systems," the article says.

The authors are Eric T. Juengst, director of the Center for Bioethics and professor in the Departments of Social Medicine and Genetics at the University of North Carolina, Chapel Hill; Michael A. Flatt, a doctoral candidate in sociology at Case Western Reserve University; and Richard A. Settersten, Jr., professor of social and behavioral health sciences and endowed director of the Hallie E. Ford Center for Healthy Children and Families in the College of Public Health and Human Sciences at Oregon State University.

In a commentary on the article, Ronni Sandroff, editorial director of Health and Family at Consumer Reports, acknowledges that pharmacogenomics could take control away from a patient if a health insurance company opted not to cover a medicine that was shown to work infrequently in people with a particular genetic makeup. But even an increase in patient empowerment can have downsides if it shifts the responsibility for [health care](#) to patients and stigmatizes people who do not, or cannot, make the "right" health choices. Sandroff notes that the greatest challenge in preventive medicine is getting people to eat less, exercise more, and reduce stress. Whether or not genetic susceptibility information will actually empower patients by propelling them toward healthier lifestyles is unknown. "This is a question that needs more serious study," she writes.

Still, Sandroff says that consumer participation in genetic health research – "a new and growing factor" – could help advance scientific knowledge. "That makes it something that professionals should be wondering how to enhance and encourage, rather than fear," she writes.

Provided by The Hastings Center

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