

With growing US support for personalized medicine, a look at ethical dilemmas

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As government support for personalized medicine grows, a consumer advocate, a patient, and bioethicists explore ethical controversies. Direct-to-consumer genetic tests, privacy, targeted cancer therapies, and Henrietta Lacks are among topics in a special issue of the [Hastings center Report](#).

Behind the high expectations raised by personalized medicine - the use of [genetic information](#) to individualize treatment, improve care, and possibly save money - a series of essays in the Hastings Center Report examines the challenges in determining what is effective; benefits and drawbacks for patients; and consumers' right to their genetic information, however imperfect. Ronni Sandroff, an editorial director of Consumer Reports, writes on controversies surrounding direct-to-consumer tests and discusses her essay in a [podcast](#).

"The Prospects for Personalized Medicine." A roundup of recent government initiatives to promote personalized medicine, successes with genetically customized drug treatments, and quality control problems with genetic tests is given by Shara Yurkiewicz, a first-year student at Harvard Medical School.

"Personalized Medicine's Ragged Edge." How should we determine who should get expensive treatments? If there were a thick, bright line separating the minimal responders from the maximal responders, then we could allocate these treatments fairly. But the reality, explains Leonard Fleck, a bioethicist at Michigan State University, is more like a

ragged edge - some people will clearly benefit a lot, some people will clearly not benefit at all, and many people will benefit somewhat.

"Personalized Cancer Care in an Age of Anxiety." To get an idea of how personalized medicine could reshape patient care in the years ahead, one need only look at how it is beginning to reshape the care of patients with cancer, writes Susan Gilbert, Hastings Center staff writer, who surveys those changes.

"A Patient's Experience." Marian Fontana, a New York author, describes her experience with genetic testing to guide her treatment for breast cancer.

"Direct-to-Consumer Genetic Tests and the Right to Know." Ronni Sandroff, editorial director, Family and Health, of Consumer Reports, appraises the young DTC [genetic testing](#) industry in the wake of recent government investigations that exposed inaccuracies and other problems. She argues against having doctors as gatekeepers of genetic information and favors government regulation to insure that the DTC tests are reliable and are not used as marketing devices for unproven products.

"Wanted: Human Biospecimens." For [personalized medicine](#) to realize its potential, researchers will need thousands of samples of human tissue, blood, urine, and other biospecimens for genetic studies, writes Karen Maschke, a Hastings Center research scholar. But this need has raised many ethical issues around informed consent and privacy, rendered vividly by recent events, including lawsuits involving use of newborn screening blood samples for research, a legal settlement with the Havasupai Indian tribe over genetic research with their blood, and publication of the bestselling book on the "immortal cells" of Henrietta Lacks.

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