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VA wants DNA from veterans

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Sun Washington Bureau

WASHINGTON - Researchers at U.S. companies, nonprofit groups and government agencies are scouring the human genome for links to common diseases, promising a day when doctors will use a patient's genetic profile to take preventative action.

One group of Americans accustomed to big sacrifices - military veterans - soon will be asked to volunteer their DNA for that cause.

The Department of Veterans Affairs plans a genetic database from potentially millions of VA patients, launching into profound legal, ethical and privacy debates to claim a leading role in genetic medicine. The VA intends to collect the first 100,000 samples in fiscal 2007, which begins in October, and foresees a database as large as veterans will allow.

The department also hopes to write rules for handling a person's genetic profile while using it in research and to identify an individual's risk of diabetes, heart problems, cancers and other conditions.

"Ultimately it's for the veterans," said Dr. Joel Kupersmith, director of VA research. "We want to make sure we come out with something that is good for the veteran and something the veteran would want."

VA officials and genetics experts said they hope the effort will provide a handbook for private health care providers and corporate labs to act responsibly in the race for genetic tests and services. A mere three years since the April 2003 completion of the human genome map, genetic business is booming.

The benefits could be enormous, but some experts say so could the risks. Emerging technology makes it possible to reveal a person's strengths and weaknesses, the likelihood of medical conditions, maybe alcoholic tendencies, and reactions to specific drugs.

Concerns are growing about ownership of genetic samples, how they are obtained, and whether consent applies to unforeseen uses years in the future. Watchdog groups worry about genetic discrimination by insurance companies and employers.

Many veterans already are wary of Uncle Sam, remembering that their ranks have been exposed to chemical agents on the battlefield and in secret human experiments.

"They are very suspicious, and they value their privacy," said Cathy Wiblemo, deputy

director of health care for the American Legion, "and I think there will be reluctance. There will be big reluctance."

Risks and benefits

VA officials said samples would be taken only with permission. VA Secretary Jim Nicholson has appointed a panel, mostly of respected geneticists, to hash out issues surrounding the project.

If a person is at genetic risk of diabetes but has no symptoms, what course should doctors take? If a person has a 1 percent chance of developing a severe cancer later in life, should he be told? Who should have access to that information?

Those are just samples of the panel's chore.

Dr. Wayne Grody, a professor of pathology, pediatrics and human genetics at the University of California at Los Angeles, said he hopes veterans will see the project as a benefit.

"We're going to proceed cautiously, with all the right controls in place," said Grody, chairman of the VA Genomic Medicine Program Advisory Committee.

The National Institutes of Health, the Centers for Disease Control and other research organizations and universities have built genetic databases for research, some with hundreds of samples and others with thousands. But several experts said there is nothing in this country of the scope or scale the VA envisions.

Iceland, the leader among a handful of countries with national health care systems that have amassed genetic databases, has been collecting samples from its 280,000 people. Some have objected.

Many geneticists see the VA as America's ideal system for large-scale research and, later, individualized medicine based on those findings and a patient's genetic code.

The VA essentially acts as provider and insurer for 7.7 million people. It uses one of the most sophisticated electronic patient record systems in the country and has a research arm that has led advances in many fields.

"The VA is the perfect breeding ground to start collecting this data," said Dave Gorman, executive director of the Disabled American Veterans, who is the only representative of veterans on the nine-member advisory panel. "There's an opportunity to do an awful lot of good out there."

VA officials said the first 100,000 samples are a preliminary step to learn about costs and practical issues while the committee does its work. The panel has not yet met, but Nicholson is touting it.

"There are so many questions of ethics and privacy that we are not going to proceed down that trail without first assessing the risks and benefits to our veterans," Nicholson said in a speech last month. "But we know from past experience that once we determine that a VA program is in the best interest of our veterans, we move forward with all the resources we can muster."

VA officials said the department is compelled to jump into this expanding field.

Just last week, researchers for the CDC reported they identified genes responsible for chronic fatigue syndrome, a condition often associated with soldiers from the first Gulf War who returned with difficult-to-diagnose problems that the VA has studied for years.

Suddenly, better diagnosis and treatment of chronic fatigue syndrome seem on the horizon. "Genetics is in pretty deep weeds right now because we put billions of dollars into basic scientific research to sequence the human genome and very little in the transitional aspects of moving it into health care," said Michael Watson, executive director of the American College of Medical Genetics, who is on VA committee.

Prenatal screening for genetic disorders is old news, and the number of possible tests has grown to about 1,000, mostly for rare disorders.

Now doctors are hunting for genes and combinations of genes pointing to more common problems.

But veterans, and the American public, must be convinced that being in a genetic database is safe.

"There are a number of things here that are problematic," said Sujatha Byravan, president of the Council for Responsible Genetics, a watchdog group.

Grody, however, said he believes privacy and discrimination concerns deserve attention but are overblown. For one thing, he said, insurers and employers might only learn in detail what we already know: That everyone has flaws.

"We're all going to end up in the same risk pool because we all carry a number of deleterious conditions," Grody said. "This might be the great equalizer."
