



# HHS Committee Urges Genetics Education Effort

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By Matt Jones

NEW YORK (GenomeWeb News) – Advances in genomics and personalized medicine are moving genetic tests into doctors' practices and patients' lives, but steps should be taken to keep healthcare professionals, doctors, and consumers educated and prepared to understand the results of these tests, according to a new report from a US Department of Health and Human Services' committee.

The Secretary's Advisory Committee on Genetics, Health and Society has issued a new draft report with proposals aimed at enhancing genomic medicine education and training for doctors and patients.

The report offers proposals concerning a number of issues, including a workshop that would develop ways to integrate genetics into clinical care; development of new training and teaching models; using family health histories in new ways; and proposing reimbursement for the time healthcare providers spend with patients discussing genetic test results and collecting family histories.

The [report](#), "Genetics Education and Training of Health Care Professionals, Public Health Providers, and Consumers," was the result of a multi-year effort at SACGHS that began in 2004, and HHS is currently seeking public comments on it.

The recommendations are part of an effort to spur "the government to get a little more vocal about this with the message that genetics is important to everybody," Joann Boughman, who is executive VP of the American Society of Human Genetics, told *GenomeWeb Daily News* today.

"One of our biggest challenges is that anybody who went to school five or 10 years ago is so far behind the curve in basic understanding of genomics that we have this huge challenge out there to get people to continue medical education and lifelong learning" on genomics, said Boughman, who also serves on the SACGHS Genetics Education and Training Task Force that produced the report.

Because the costs of genomic sequencing, genotyping, and DNA data analysis keeps dropping, and because the clinical utility of genetic tests and services is likely to be demonstrated over time, the report concludes, health care professionals will be more likely to see the need to incorporate genetics and genomics into their practices and both they and their patients will need a greater understanding of these fields.

This set of recommendations from the 17-member task force was developed through reviews of relevant literature and surveys of select organizations, groups, and individuals with interests or expertise in genetics education.

The focus throughout was on three groups: health care professionals, public health providers, and patients and consumers.

"Rather than just trying to choose just one group we decided to pull together all three groups because we see them really interrelated – the consumer's needs are related to what the providers are saying and we all access public health," Barbara Burns McGrath, chair of the SACGHS task force and a research associate at the University of Washington School of Nursing, told *GWDN* yesterday.

First, the task force has recommended that HHS convene a workshop to identify innovative education and training approaches to integrate genetics and genomics into clinical care. The workshop would aim to identify new education and training guidelines, find new funding streams to pay for new initiatives, plan to enhance the content of genetics and personalized medicine education, offer ideas for developing new and relevant educational standards, consider appointing an ongoing advisory panel, and develop a plan to monitor the outcome of its efforts.

McGrath said that the workshop will be an "out-of-the-box thinking" effort to approach the "unique" problems of genomics.

"Genomics is kind of an interesting field ... in that it's such a fast-moving target and we have a lot of technologies out there. We haven't established the utility of a lot of them, but there's a lot of promise out there," she explained.

"What we need is some sort of forward-thinking group to get together and talk about how do we not only meet the needs for today ... [but] how do we plan for the future," she said.

The second recommendation advises promoting the development of targeted training models for health care professionals working in underserved populations.

Another proposal is for HHS to use the expertise of agencies already involved in genetics education to understand current trends and future needs. This effort would involve incorporating basic genetic and genomics core competencies in health care providers' education programs.

"There is a challenge in [genetics training programs, because] until practicing physicians see the usefulness of genetics in their practice it's a little difficult to expect them to fully embrace education," McGrath pointed out.

The task force also recommended that HHS maintain an internet portal containing a well-vetted collection of web-based information and resources for consumers on genetic testing and genomics, such as those already developed by the National Institutes of Health and the Centers for Disease Control and Prevention.

The SACGHS report also has urged support for research that identifies which methods are best for communicating with patients and consumers, including educational programs using media outreach and collaborations with agencies such as the Department of Education and the National Science Foundation.

Reimbursement for genetic testing and consultations with doctors is viewed as "a critical step" in promoting more knowledge of genomics among doctors, the report states, because without pay there is little incentive for doctors to spend much time on interpreting genetic information and gathering family histories.

Boughman said that many students now "are not interested in coming into genetics because they are not well reimbursed."

"They don't make as much as many of their peers. What happens is that somebody trained as a geneticist ends up at academic health centers ... and some days they're doing research, and some days they're seeing patients, and some days they're teaching and that is just not enough to support the system given that the field is moving so rapidly. [Geneticists] may spend an hour-and-a-half with a patient and we only get reimbursed for thirty minutes," she added.

To tackle these issues, the SACGHS report recommended that HHS ensure adequate reimbursement for health care professional time spent in direct patient care discussing these issues, as well as for teams providing genetic services and for distance consultation and telemedicine services used in underserved regions.

The task force also wants HHS to support efforts to educate health care professionals, providers, and patients about the value of family histories in medical care. It recommends supporting the use of family history in clinical care by developing new support tools and integrating histories in electronic medical records, as well as researching how consumers use their histories and addressing them directly through awareness campaigns.

"Now that this report will become public I would not be surprised if some of the HHS agencies like NIH, or CDC, or Health Resources Services Administration don't see this as a call to action," said Boughman. "We're sincerely hoping that they do."

McGrath said that the task force wanted its proposals to offer "actionable" ideas that HHS can pursue.

"Washington's full of recommendations that can't really be measured, so we tried to make ours as measurable as possible," McGrath said, adding that she expects some of them to be revamped after the task force reviews the comments that will come in from the public and stakeholders.

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