

*Federal Efforts to Address Genetics Workforce, Education and Training Issues*  
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Dr. Shekar is the ex officio representing HRSA and has brought together to report to us the activities of the various agencies that he will tell us about in that report.

Dr. Shekar, thank you.

DR. SHEKAR: Thank you very much, Dr. McCabe. I appreciate being here today. I was asked to speak on behalf of the ex officio federal agencies of this committee regarding the issue of genetics education and training professionals. I thank the committee for the opportunity.

I thank my colleagues in the agencies who took a lot of time to help focus and to help respond to the survey. It provides a unique opportunity look across 16 agencies participating as ex officio members of the committee.

A special thank you to the SACGHS staff for putting that survey together, compiling the data, and preparing the report, and a very special thank you to Dr. Suzanne Feetham for her continued support and guidance on our own HRSA genetics activities and helping to represent us here the many times that you've had these meetings and continue to.

As reported by the Institute of Medicine and others, there is at least a 10-year time lag of translating relevant science from the laboratory to general application across the people. Some examples of the rapid advances in genomics with application for health were presented yesterday and by Dr. Collins in the first SACGHS meeting. With the exponential growth of genetic science and genomics, this lag time is not going to be very acceptable. In order to be positioned for 2010 and beyond, we must address this now, for there are over 11 million health care professionals with over 200 professional titles who must eventually serve as some of our principal partners in translating genetics into everyday practice, as Dr. Boughman had mentioned earlier with her apocryphal example of a family practitioner asking, "What does this mean now? What does this mean in my daily practice?"

At SACGHS' inaugural meeting in June, the committee identified genetics education and training of professionals and the adequacy of the genetics workforce as areas of interest and priority. You requested additional information about federal and private sector efforts to address that need.

It's important to note that the primary role and responsibility for education and training of professionals lies in the non-federal private sector, with the academies and with the professions, and we absolutely understand that and want to serve as partners with you to make this happen.

You'll be hearing about many of the genetics education efforts being undertaken by the private sector later today. On behalf of my federal colleagues, I'm pleased to present the information you requested on the federal activities in this area.

A copy of the survey instrument and three parts of the agency submissions are in Tab 6 of your briefing books. Around the meeting table are several copies of each agency's entire submissions for pleasure reading tonight, including the detailed descriptions of their individual projects.

The survey consisted of four parts, a Part 1 narrative summary; Part 2, which was lists of relevant

activities; Part 3, detailed description of each activity, including target audiences, partnerships, and impact; and Part 4, funding of these relevant activities from fiscal year 2000 to fiscal year '03.

The intent in asking for funding levels was to obtain a general sense of the total investment across the agencies, not to make comparisons across the agencies, but to give a general sense of where we are for the federal government.

It is important to note that there may be some underreporting of activities because of a couple of reasons. First is that there are other federal agencies, as we all know, that are not necessarily ex officio members of this committee and obviously were not included in this survey, but could in fact be doing genetics activities. Second, the time provided was extremely short in order to meet the deadlines, less than a month, so therefore the breadth and depth of activities in genetics and genomics may not be quite complete through some of even the agencies surveyed.

As you know, agencies were asked to describe the mission-relatedness of the efforts, the decisionmaking criteria, specific needs that were being addressed, and results of any program evaluations.

Seven agencies reported having over 180 relevant activities, and you see some of them listed here, and this being Washington, we can only describe things in acronyms. So there you go.

Eight agencies reported having no relevant activities. It's important to note that the non-reporting agencies are nonetheless carrying out critical education and outreach activities in a broad range of areas which include, as part of it, some genetic components. For example, the Office for Human Research Protections, OHRP, is undertaking important work with respect to revising guidance for genetics research and other research, the Office of Civil Rights is conducting critical outreach and education around HIPAA privacy regulations which have some impact on genomics and genetics, and so forth and so on.

The fundamental need addressed by the federal efforts was simple and clearcut: facilitating the translation of genetics into practice.

As noted, the Human Genome Project and other genetics research has increased the pace and amount of genetics research and created higher expectations for the application of genetics knowledge and technologies in medical, health care, public health, legal, and other arenas. The federal government realizes that the science of genetics has advanced well beyond the genetics knowledge base of many health professionals and that professionals play and will play a greater critical role in integrating genomics into practice.

Questions were raised yesterday, as I understand, as to what is different about this genetics knowledge. The premise from the federal agencies is that genetics/genomics will become a central science for the practice of health professionals, increasing our knowledge of mechanisms of diseases and conditions for diagnosis, treatment, prevention, and health promotion, and providing a new lens for all health professionals, particularly those in primary care. As presented in the pharmacogenomic examples yesterday, there is opportunity through that to provide more focus for individualized or targeted care.

Agencies are thinking comprehensively across the system, choosing activities in a systematic way, and integrating those efforts across their agencies, doing this through partnerships with local, state, and federal organizations, developing expert recommendations, working with stakeholders, and assessing impacts of funds.

An indicator of the complementary roles that I've mentioned is that from a rough hand count of the responses from just three agencies alone -- CDC, NIH, and HRSA -- each reported partnerships with other

federal agencies for about a fifth of the activities that they engaged in, and the partners most frequently cited were those agencies themselves, along with other agencies, such as the Department of Energy. Most activities are complementary, due to significant agency cooperation which will increase over time, and also target a broad range of audiences.

Clearly, health professionals are the primary target, but what's of interest is many other professionals are also targeted as we think about, as Dr. Boughman mentioned earlier, our ultimate stakeholders, the general public. So clergy, journalists, teachers, underserved populations, judges, lawyers, law enforcement personnel, all these individuals, all these professionals, are also targets of genomics and genetics education and training, and that will also increase over time.

Most agencies support a variety of activities in education and training, including dissemination, educational outreach, consensus building, and generalized training, either directly or online.

An example is the Genetic Interdisciplinary Faculty Training Program at Duke University funded by HRSA's Bureau of Health Professions, which, primarily through four approaches, provides greater understanding of genetics and genomics, focusing on curriculum revisions, presentations, publications, and web-based resources. We were able, through this activity funded at around three-quarters of a million dollars, to arrange for 22 regional, national, and international presentations and articles, 34 courses, graduate program lectures that were incorporated into faculty teachings by three interdisciplinary teams, three research studies, over 2,000 hits on an online module, 3,000 brochures distributed, et cetera, et cetera. It's important to note that the teams were interdisciplinary and included members from nursing, medical, and many other professional groups.

This grant included, as I said, 16 interdisciplinary teams from 13 states. It started off with six states in 2002 and expanded over time and now has gone beyond 10 teams in 10 states, as noted on the map. There was also an earlier activity called the Genetics in Primary Care Project, which was a partnership led by HRSA, but also with very strong partnership from NIH, CDC, and AHRQ, where 20 physician teams in 19 states provided that training in genomics, and now there's a website being developed to expand into other disciplines.

The Department of Energy's Genetics Adjudication Resource Project at the Einstein Institute for Science, Health, and the Courts worked on a number of projects to help inform judges about the advances in genomics, and it funded 38 workshops to train 3,300 judges through a \$1.5 million project to have them understand the implications of genomics for society and law. This was a model that was then replicated and advanced in other programs, such as the Judicial Conference for the upper New England states, as well as the Genetics Conference for Clergy organized by Catholic University focusing on the ethical, legal, societal, and personal challenges that may arise from genomics.

The total funds spent by those surveyed in the agencies were roughly over \$100 million, \$102 million, to be exact. HRSA carried out the greatest number of activities in health professional education and training in terms of funds spent. NIH had the highest figures in all four fiscal years. Again, this is a retrospective estimate of discretionary actions taken over a very short time period in terms of the survey. So again, there may be some underreporting going on, but federal agencies have generally not made specific resource allocations to genetics education activities, but have incorporated that among their other training and education missions.

The very good news is that this funding represents not only a significant amount across four years, but an ever-increasing amount, as you can see from this slide. A steady increase in the overall funding at federal levels for activities in education and training in genetics and workforce analysis reflects the emerging importance of genetics in the clinical sphere.

The federal government realizes that the science of genetics has advanced beyond the practitioner's general knowledge level in genetics and that health professionals play a critical role in integrating genomics into practice. In response to these developments, federal agencies, as you can see, are taking and will take an even greater leadership role in helping to advance the training and education of professionals in partnership with societies and private sector colleagues.

Of note is our own little Hawthorne effect through the survey. Participation in the survey is resulting in increased dialogue, even more increased dialogue, among some of the federal agencies that participated.

A few summary observations. Genetics education, training, and workforce analysis efforts are supported by discretionary funding. Discretionary funding is very flexible and is critical to allowing agencies to respond to new needs as they arise. However, as we know, when multiple needs arise simultaneously, that funding has a degree of support concerns that then needs to be looked at.

Under workforce analysis, it is very important to understand who is out there to provide that genomics education, but it is not the only factor to be thinking about. In fact, the pace of scientific discovery and the general applicability of genomic advances -- the family practitioner example that was quoted earlier -- to common diseases and conditions will also help determine the health workforce balance that's needed to provide the adequate support to serve the general population, and obviously, additional evaluation efforts at the project, and possibly agency, level may be needed.

It's clear that agencies are helping to look at the genetics evolution and revolution, and two major action items were identified in the survey by the agencies as helping to really push this whole focus forward: helping with our partners to identify the appropriate use of new genetics knowledge and technologies and also helping with the across-the-board integration into general practice across multiple professional groups and across multiple locations. Are the issues the same in urban areas as they are in rural areas? Are they the same for different populations?

In conclusion, the agencies look forward to working with SACGHS and the private sector as we all proceed with these great advances in science and, ultimately, practice to help improve the health of this nation.

Thank you.