Presentation on Information Gathered on Efforts in Genetics Education and Training
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So next, we're actually running just a little bit ahead of time, but we're going to have a presentation on information gathered on efforts in genetics education and training by Dr. Joan Reede. Dr. Reede will review the education task force's information gathering efforts over the last three months. I'd like to thank Joan for your chairing the task force, as well as Kim Zellmer, Hunt Willard, Barbara Harrison, and Agnes Masny for your service on the task force. We appreciate the time and effort that all of you have put into gathering the data and preparing the draft resolution. Joan, please proceed.

DR. REEDE: Thank you very much, and thank you for the opportunity to present the work of the task force.

You just mentioned the names of the members of that task force, but I also want to acknowledge the staff who supported us. Amanda Sarata did a wonderful job of helping to facilitate our meetings, moving this forward, and helping to put this presentation together.

During the discussions of genetic education and training at the March meeting, the committee decided to draft a resolution to the Secretary on the issue of genetics education and training, outlining key recommendations in this area. Toward this end, they decided that a task force should be established with these charges to collect information on the activities of health professional organizations that relate to genetics education and training, to organize and facilitate a roundtable discussion to be held during this June meeting, and to draft a resolution to the Secretary on genetics education and training.

The committee's request to hear formally from professional organizations in the private sector on their activities in genetics education and training was meant to serve as a follow up to, or addition to the survey of federal agencies on their activities, as well as the presentation and information from Joann Boughman at the October meeting.

It was felt that this information would be used to inform our resolution, and should ensure that any recommendations made to the federal government would be complementary to activities already ongoing in the private sector. We solicited information from 26 organizations.

The organizations can be divided into three categories. Genetic-specific organizations, health professional educational organizations, organizations involved in the education of health professionals, and health profession organizations. The latter really targeting three groups, those that represent generalists such as AMA, those representing specialities such as family practitioners, pediatricians, OB/GYN, and those representing specific constituencies, such as the National Medical Association, AAIP, and NHMA.

Of note, we had only a maximum of nine organizations in each category, and this was really to be consistent with guidelines so that we would not have to turn to OMB for review of our survey of the organizations. Fifteen of the 26 organizations responded, which is a fairly good response for a three-week period from when the surveys went out. Of note, however, we shouldn't assume that the groups that we did not hear from do not have important activities in these areas.

Here is a list of the organizations that responded. You'll be hearing from some of these organizations during the roundtable discussion, as well as some additional organizations that did

not get their responses in in time for this.

In addition to having information that represents organizations, it is also important to note that this information represents multiple specialties or disciplines. There is information on nurses, geneticists, allied health professionals, dentists, pharmacists, and physicians.

With regard to the three categories, I will go through them in sequence. The first is on genetic-specific organizations. The committee felt that it was important to solicit information from organizations who are focused on the issues of genetics. This provided the committee with the information about the "state of the state," which is currently going on within organizations that have a high awareness of and focus on genetics and genomics.

We have already benefitted greatly from their input on many issues, and appreciate their willingness to continue providing their input. We highlighted three important areas of potential gaps in our understanding. These were diversity, life insurance certification, and curricular development.

We wanted to know about current initiatives and activities that related to diversity in the genetics workforce, that enhanced genetics and genomics curricula, and that promoted the incorporation of genetics and genomics content into licensure and certification.

Diversity in the genetics work force is an important issue to the committee. Genetics is a field where both cultural diversity and cultural competency are particularly relevant, the impact of culture on perceptions of attitudes about genetics, and also in the area of the debate about the scientific basis of race and its place in medicine and genetics.

What we found was that these organizations were involved in many activities that targeted both the pipeline, such as those involving K through 12 education, as well as the recruitment of individuals from diverse backgrounds into genetic counseling.

These efforts also targeted minority health professionals, minorities who attended colleges, high schools, colleges and universities, and also at the organizational level brought diversity in through structural forms, such as the organization of a diversity standing subcommittee.

With regard to curricula, it appears that genetic-specific groups are leaders in the development of genetic curriculum, and are actively engaged in dissemination and outreach efforts to other health professionals. They are engaged in activities such as speakers bureaus, short courses, conferences, as well as the dissemination of position papers and practice guidelines.

The core competencies provide universal guidance, and the core competencies have been a major effort on the part of these genetic-specific organizations. It was felt that specialty-specific competencies could be determined by professional societies, and the use of the Internet to disseminate and share information was also felt to be critical.

Increasingly, medicine will become more electronic, and genetics, being a field that changes rapidly and involves large amounts of information, benefits from this change. It was felt that educational materials should conform to this trend.

Courses to train faculty to teach genetics content is a key element. This matches up with a barrier that was noted by another category, the Health Professional Educational Organizations, feeling that there was a lack of appropriately prepared faculty for genetics training and education.

Licensure, certification, and accreditation have the potential to change behavior, and increase integration of genetics and genomics knowledge throughout the health care system. Although many of the agencies did not report a great deal of activity in these areas, some of the types of activities that they are engaged in included credentialing programs in genetics, use of core competencies to help inform discussions or programs related to licensure and certification, and biannual genetics review courses.

The issue of licensure certification and accreditation can require several different types of specific policy solutions. Part of this is related to the fact that there are different factors across the board here. In licensure, oftentimes we're dealing with state certifications, we're dealing with specialty professional societies in the federal government such as with CLIA, and accreditation, and we're dealing with private organizations, such as JCAHO.

The overall recommendation from this group was that "we should be strong in our appeal to helping the HHS Secretary to actively support a wide variety of endeavors based in or funded by any of the HHS-based agencies, as well as seeking partnerships with other relevant federal agencies."

The second category. Those organizations that are involved in the education of health professionals. For this category, these questions deal with curricula development for education of health professionals. With these questions, we are trying to gauge where genetics/genomics stands in health education organizations that have a general, rather than a specific, genetics focus.

The question for this group included those about the need for the integration of genetics and genomics in their curriculum, barriers to this integration, and current ongoing activities and initiatives.

With regard to their perceived needs, there is a need to acknowledge that genetic science is for both generalists and specialists. This points out the tension between educating everyone, and maintaining a niche for specialists. General practitioners have an important role to play in integrating genetics and genomics in health care, and specialists will also play a necessary role in that new paradigm.

Due to the complexity of and the speed at which the genetics field is evolving, there is also a need for improved access to knowledge, and this was cited by many organizations. There is a need to be able to evaluate product claims. This comment ties to the committee's interest in and focus on direct-to-consumer marketing and advertising. Education will facilitate provider's ability to assess the validity, efficacy, and safety of various new products for their patients.

There is a need to redefine and recast genetics as an inherent and overarching part of health and to improve communication between all health professionals and the public about how genetics affects health. In keeping with the theme that genetics is relevant to all specialties in medicine, and will be an important part of all aspects of clinical management of the patient, from prevention, diagnosis, and treatment perspectives.

There was a perceived need to determine the level of knowledge that is needed, who needs to know what, and who should provide that, and also the need to provide tools for lifelong learning. This last comment highlights the fact that genetics and genomics knowledge will be rapidly changing, and therefore, education should be a lifelong pursuit.

With regard to barriers, it was difficult to find current case examples or models. This comment represents an important theme that was raised by several organizations in response to many different questions. In order to teach genetics and genomics, models using clinically relevant examples are needed. There is a lack of trained faculty broadly competent in genetics and genomics, and it is expected that there will be a lack of uniformity in the rate of integration of genetics into the various specialties in medicine. This, in turn, will make it difficult to determine who should be learning what, and when.

Other barriers include difficulty in motivating students to learn something based on the promise of its "future importance," an overcrowded curricula that is already struggling with issues of basic science and clinical practice, and the fact that genetics by many is still considered to be an esoteric field.

Current activities from health professional educational organizations include membership in NCHPEG, integrating those core competencies that have been identified by NCHPEG into their entry-level competencies for their specialties, or their special disciplines, and the serving of faculty competency in and understanding of genetics/genomics.

With regard to current activities, one organization is sponsoring relevant legislation of the allied health professions that would help support curricular development in the area of genetics and genomics. Overall, it was felt that cultural competency was addressed broadly within the context of outreach to underserved populations, and there was no specific focus on the area of genetics.

Recommendations from these organizations included that schools and professional organizations must provide leadership in preparing the next generation of health professionals in genetics. The primary role of preparing health professionals lies with the schools and professional organizations, not with the federal government.

Continuing education is needed to train the trainer, and this specifically refers to helping clinicians to determine when to refer, how to obtain information about genetics research studies, and ways to discuss research options with patients. More funding is needed to support training and education in genetic technologies, and to facilitate the incorporation of new knowledge and skills.

With regard to the last set of organizations, the health professional organization responses, the committee reasoned that it was also important to gather information from umbrella organizations that focused on specific health professional disciplines. These responses provide the committee with useful information on the relative importance of genetics to organizations grappling with many other equally important issues.

The information may also be an indicator of how genetics and genomics is perceived within the health care system generally. The types of questions that were asked of this group include characterizing the need for integration of genetics and genomics, what types of activities or initiatives they have currently ongoing, and in here, we ask specifically about partnerships, about interdisciplinary efforts, about educational products, and about outcomes, what has been evaluated, and the impact.

We asked them specifically about steps they were taking with regard to diversity, and about their particular concerns and recommendations that they would like our committee to make. With regards to their needs, they felt that all health processionals need a strong, knowledge-base in genetics and genetics testing.

Identifying clinically-relevant examples of genetics and genomics would help address the need to understand how genetics interfaces with practice. You hear a recurring theme of the need for applications, and there is a need to understand how this relates to practice.

There is a need to help professionals with
up-to-date advances in genetics. This is brought by many health professional organizations in terms of the need for access to new knowledge. Again, we have the issue of lifelong learning, keeping up to date. In terms of current activities, the health professional organizations are undertaking a broad array of activities related to genetics education and training. Some are using traditional tools for consensus building and dissemination. You see a wide range from CME educational sessions, to web-based educational tools, to newspaper articles, journal articles, symposia, and across the board.

With regards to their current activities and their interdisciplinary nature or partnerships, several of the organizations are partnering with others, federal agencies, genetic specialty societies, medical societies, non-profit organizations, and private companies. The majority of the organizations report that their activities are interdisciplinary in nature.

With regards to outcome and evaluation, it was found that most of the organizations measured their outcomes or evaluation based on increasing interest, or continued interest, and in issues related to genetics and genomics. This was gathered by looking at numbers who attended genetic sessions at national meetings, hits to genetics websites, CME certificates, and distribution of educational materials.

Current activities related to diversity take many forms, from community outreach, career development, education, research, advocacy, and organizational position statements. Concerns of this last group of organizations. The science underlying issues of race in medicine needs to be examined and integrated into genetics education and training.

Issues of race in genetics necessitate special consideration and treatment in the educational setting. Awareness of these issues is an important part of a health practitioner's cultural competency. For many physicians, genetics does not have immediate, daily, and clinical applicability.

This comment relates to the need to understand how genetics interfaces with practice, and the barriers caused by the difficulty in finding case examples or models in genetics and genomics cited by health professional organizations previously.

To quote one person, "Genomics is spinach. Everybody knows it is good for them, but nobody likes it." Genetics education must be represented throughout the entire continuum of medical education. There is a need for tools that facilitate this lifelong learning, and a need to keep professionals up to date.

Additional concerns. Educational programs must have a focus on pediatrics and genetics, and physicians prefer interactive learning with case studies. The effect of the nursing shortage on patient education and informed consent was also raised. It was felt that this point might raise the broader question of the impact with the emphasis on efficacy in our system might have on integration of a rather time intensive and complex issue, like genomics.

Recommendations from this third set of organizations. Ongoing, continuing education should be

the responsibility of the licensing agencies and professional organizations. The development of profession-specific materials should be left to the health professions. The support for genetic education programs would be an appropriate role for the government.

Further recommendations. Funding is needed for new programs that feature educational practices known to change physician behavior. This includes areas such as learning based on perceived need, and interactive learning. Efforts in genetics education must extend to related areas of molecular medicine, and benchmarks should be instituted to inform and assess the bidirectional impact of translational research, i.e. from bench to bedside, and bedside to bench.

Recommendations. Education and training should address population-based genetic variation, and its utility in the emerging era of individualized medicine. The impact of genetic polymorphisms on the determination of "what is normal" in the era of molecular medicine, the scientific relevance and significance of minority participation in clinical trials, to the quality of health care in a merging era of genomic medicine, and the diagnostic importance of obtaining a good and complete family history on all patients.

Turning now to our second charge, which relates to the educational roundtable. The purpose and goals of this were to discuss in detail, the organization's efforts in and attitudes about genetics education and training, and to add to the information already provided in the surveys, to identify key concerns and barriers with respect to these issues on the organizational level, and to help inform any resolution coming from this committee to the Secretary.

The organizations that will be involved in this roundtable are listed here. Our representatives will be introduced to you formally later.

In the third area, we were asked to develop a draft resolution that could go to the Secretary with regards to education and training. The purpose is to arrive at a consensus of the committee on the issue of education and training, to convey this consensus to the Secretary, and to make recommendations or possible steps to address this important issue.

The conclusions that we had were that genomics can improve health, that adequate education and training in genetics and genomics is essential to integrating genetics into the health care system, and that access is contingent upon effective integration.

Additionally, the education professional organizations identified the following needs. There is a need for inventoried, widely-relevant clinical applications, a recurring theme, educational models that use such applications, and a broadened focus from genetics to genomics. There is also a need for appropriately trained faculty, and training programs that address genetics/genomics, and public policy.

With regard to our task force education resolution recommendations, there were six. We decided that while genetics is important and special, in that it is relevant to all areas of medicine and health care, it would be inappropriate to single it out in the educational setting. Rather, it should be integrated throughout all stages of learning, in all settings, and throughout all disciplines.

There is a need to support programs that enhance diversity among cultural competency of health professions. We need to engage other stakeholders in the process of cataloging genomics applications to clinical medicine and public health. This third recommendation addresses the concern about the lack of clinically relevant genomics and genetics applications.

Fourth, we need to support programs that "train the trainers" in genomics and genetics education, addressing the identification of barriers to the lack of professionals trained to teach genetics. Fifth, we need to promote communication between faculty to enhance use of genomics educational models. And last, to encourage incorporation of genetics and genomics into the certification and licensure process.

Thank you.

DR. McCABE: Thank you very much, Dr. Reede.

At this time, let's take a 15-minute break. The members of the committee and our ex officios are invited to enjoy the refreshments here at the front of the room. For members of the public, refreshments and beverages are available at the gift shop near the hotel lobby.

We will reconvene in 15 minutes. That will be at about five of the hour. Thank you.