

Presentation of Proposed Action Plan of SACGHS Task Force on Education and Training
Barbara Burns McGrath, R.N., Ph.D.

DR. TEUTSCH: This afternoon we have two additional things. We are going to get, first, an update from Barbara Burns McGrath on the Education and Training Task force. I will turn it over to her, and then we will wrap up with a discussion on the priorities and the follow-up on this morning's discussion. Barbara.

We are scheduled until 2:05. If you can do by 2:10, it would be lovely. If you can.

DR. McGRATH: We will all watch the clock together.

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DR. McGRATH: I'm going to be talking 10 or 15 minutes about the Education and Training Task force. We will show the membership in just a moment.

This is an issue that has resurfaced a lot in the last two days. Yesterday when we did our priority scanning, we did a little look and there were four topics that explicitly listed genetics education and training of the work force that rose to the hot level on the scan, the 3.5 level and above. So it was very high on the priority list.

Yesterday afternoon and today the topic kept recircling on even the ones that didn't meet the 3.5 level yesterday. I was noticing there were other areas that were throughout the priority areas that I think also come under this rubric. One is consumer access to genomic information. Health disparities can be looked at through this lens. The electronic health record and personal health record, public health applications of genomics, and coverage and reimbursement all have aspects that I think have some attachment to the notion of genetics education and training.

In yesterday afternoon's session and this morning that issue came up a lot again, and it got to have a sense that whatever the question was where there was a particular dilemma the answer was better training for professionals and consumers was the answer to it.

I think this topic was one that was identified with the first SAC group when it was originally formed in 2002, I think it was. It has resurfaced now, and I don't think it is going to go away. I think we are ready to roll up our sleeves and work on this one.

These are the committee members. There are going to be a few changes, but basically that is who has been working on it so far. We are always looking for more members, so if you are intrigued, contact us.

Today's purpose is to talk about two pieces of information we have, and these are under Tab 5 in your booklet. [We will] go over the revised task force charge that we worked on last time. We will talk about our activities, and we will present the draft action plan. The goal for today is to reach a consensus on both of those documents, the task force charge and the action plan.

As a quick update, at the last meeting there was a discussion and it was suggested that we narrow the scope of stakeholders. The original list was pretty long and broad. We were asked to consider various education mechanisms and modalities to be more creative than just thinking about post baccalaureate training or whatever, to focus on issues specific to genetics and actionable by HHS, to narrow it not to things like health literacy but to issues around genetics and

things where the federal government has a role to play, and of course, aim for actionable outcomes.

I'm going to read the draft charge. As I said, it is on Tab 5. I will read it fairly quickly. This is asking for your approval on the wording on this. We can talk about all of this at the end of this session so we know we have time.

This is the draft charge: "Advances in genetics and genomics are leading to a better understanding of disease processes and improved application of genetic testing to guide health decisions. With increased integration of genetics into other medical disciplines however, health professionals with or without training or expertise in genetics are challenged to keep pace with this dynamic and rapidly evolving field. Education will have to address the growing importance of genetics in common diseases, which likely will require more knowledge and understanding about risk assessment and communication. In addition, the accelerated growth of direct-to-consumer genetic services highlights the need for informed decision-making.

"To realize the benefits of genetic technologies and protect against potential harms, the education of healthcare professionals, the public health work force, and the general public is critical. For these reasons, the Secretary's Advisory Committee on Genetics, Health, and Society has formed a task force to build on the findings of the Committee's 2004 resolution on genetic education and training of health professionals."

Our draft charge then, following these aims, was one that has been modified by the Committee over the last few months. On the screen you can see the changes but in your booklet you will just see the final revised one. I will read this out loud as well. This is the draft charge that will give us our marching orders.

"The task force is charged with developing a plan to identify the education and training needs of health professionals, the public health work force, and the general public in order to optimize the benefits of genetic and genomic services for all Americans. This plan will also outline the steps required to meet these needs and evaluate the efficacy of educational and training efforts. This plan includes but is not limited to the following activities:

- 1) Assembling evidence to determine which recommendations from the 2004 SACGHS education resolution were implemented and which ones require additional efforts;
- 2) Identifying the education and training needs specific to genetics and genomics for healthcare professionals;
- 3) Identifying the education and training needs of the public health work force;"

No. 4 got scrapped.

- 5) Identifying the education needs of patients and consumers to assist them in informed decision-making about the use of genetic services and enhance their understanding and utilization of results and how these results impact decisions about prevention or treatment;

- 6) Identifying effective educational tools that can be incorporated into electronic health records, personal health records, and clinical decision support systems that would enhance the appropriate integration of genetic and genomic technologies throughout the healthcare system without

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adversely impacting privacy, access, and work flow. In addition, identify gaps where such tools do not currently exist and develop recommendations on how to address these gaps;

7) Assessing the use of evaluative research methods to determine the efficacy of genetics and genomic education and training." No. 8 got scrapped as well.

What I would like to do is hold your thoughts about any changes you might want with those until I go through some of our activities to see if that informs some of your comments.

The group had a conference call in March. We discussed these new changes of limiting the focus and broke ourselves up into three workgroups focusing on that narrower scope. We were going to focus on health professionals as one group, public health providers, and consumers and patients as the third group.

Chairs were selected for each of those subgroups. George Feero is heading the group with the health professionals, Joseph Telfair is heading the group with public health providers, and Vince Bonham is heading the group with consumers and patients.

Each workgroup then met on conference calls with their own group. The whole committee was then divided into these groups, and each group met independently to talk about their own action plans, as these were seen as fairly independent.

Then on June 3rd, about a month ago, the chairs and I and Cathy Fomous had a common conference call to see if we could integrate the activities. We came up with an action plan.

The main part of the action plan of course is to produce a report -- we are aiming for 2010 -- that will identify the gaps and make recommendations to address them.

We developed an integrated framework for how to achieve these goals and the decision was made at that point to present to you using a clinical case model to highlight all the needs of the various groups. The reason we chose a clinical case model for this was that we were looking for some way that could integrate all the different perspectives. We wanted to have a way of telling the story about what education and training is needed and the gaps in a more compelling or evocative way than just writing up a list of recommendations or competencies.

So we came up with a case model way to put a face on the experiences of the various groups, coming up with specific cases that would highlight different lenses that would be used to look through these story lines.

The frameworks that we have chosen have a couple common themes. They will each need to address the needs of the various audiences. We are trying to identify different types of testing, different stages of testing, and different settings, and then how the education or training can best be provided and evaluated in meeting all of these needs.

We came up with an initial list of seven potential case studies that we think might meet those needs and help us highlight the educational and training needs of the three groups we have identified. These are patient diagnosis of a single gene disorder, a family history of a common disease, a case with a newborn screening situation, some pharmacogenomic testing, direct-to-consumer testing, population research, and media reporting of research results, and designed a case study that highlights each one of those situations. These are in draft form and open to discussion.

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Each workgroup designed their own plan for how they want to address their needs for their own specific group. You have the longer versions in your booklet, but [I will] just highlight a few of them.

The Health Professionals Group is planning at this point to start with summarizing the literature and then mapping the existing federal ecosystem, with a plan of doing a survey of key professional organizations to identify their priorities.

The Public Health Provider Group is approaching it at this point by identifying a subset of public health providers to do an assessment of their needs. They plan to review competencies and then assess how the competencies are being met or what gaps are in there.

The Consumer and Patient Workgroup is also starting with a literature review and mapping existing activities and then consulting with experts in the field of genetics and education to identify the gaps.

The next steps of our task force or the workgroups will be executing their action plans. We are hoping to have draft findings by spring of 2009 so we can assemble a draft report for public comment by next summer and the revisions and final report by early 2010, which is fairly ambitious, but that is what we are aiming for.