

**Draft Report on Genetics Education/Training:**

**Literature and Survey Findings**

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[PowerPoint Presentation.]

DR. McGRATH: Thank you. So I think the plan is for me to present some things and then really open up the room for discussion about these.

So this is a Task Force on Education and Training. In terms of the lifespan of task forces, I think patents might be considered at the end of its life, it's ready to leave this stage.

[Laughter.]

DR. McGRATH: Speaking metaphorically. So if we think of it that way, I think our report is in its late teens with all that that might imply. Think about it as that as we're talking about it.

I wanted to put up the roster first because these are the people who are doing the heavy lifting on this committee. It looks unwieldy because it fills the slide, but it really isn't. You know all the people on there. They represent, really, a broad base of expertise and everyone's expertise has been used to some extent in this

large report.

The Committee charged us with a really big task. Because of that, we then subdivided into three groups, which in another world might be considered three separate committees or task forces, but these are considered workgroups under this big umbrella. We divided them into looking at the Education and Training Needs of Healthcare Professionals. Greg Feero started as chair on that, and David Dale has assumed that position as Greg rotated off.

The Public Health Provider Workgroup, Joseph Telfair has rotated off the SACGHS, but he has wonderfully been involved, stayed involved in the Committee, and will continue until it's over. Sylvia Au is here today, able to represent that committee if issues come up.

Consumer and Patient Group is chaired by Vence Bonham who is here, and Sarah Harding, also from his shop, has been very involved in it.

So these are the chairs of each of the workgroups, and they function very autonomously. Each of these chairs and their teams have been the ones collecting the data as well as crafting the recommendations.

Today, we'll be reviewing some of the findings of

this report, and I'll emphasize that I'm going to do it very briefly. In your briefing book is a summary of some of the findings. The full text of that report you will be receiving in January or February. So we're not providing all of the findings for you, and I'll explain why in a little bit. I'll just go over some of them, very briefly, to give you a flavor of it, but most of the time that we have today, we would like to talk about recommendations.

We're going to solicit help today in a number of areas. One is -- I say this at every meeting -- we would really like to craft these recommendations as actionable, the recommendations to the Secretary of HHS. We would like them to be something that she can take and decide what to do or not to do with them, in that, we would like to move beyond abstract and generic recommendations that cause the eyes to glaze over. I think we've all seen lots of those.

We would like to be forward-thinking about the future of genomics and not just make recommendations for today but to think about how these might anticipate trends that happen in the future.

We also are trying to be very sensitive to the reality of competing healthcare needs, and also to avoid a

GINA-centric tone or perspective to this report, and that all of education for health providers and public health officials and consumers really ought to be focused on genetics first and genetics only. So those are some areas.

We would like, in our recommendations, to be sure we are covering key points, but also, think about pruning these down to a modest number by either combining them or eliminating some that are covered in other reports or other committees, or are just redundant.

The recommendations you will see today are not final. We will be revising them over the next couple of months and putting them into the report. So we're not at the stage that we were yesterday with patents, of crafting the language and the meaning.

What we would like to do today is really focus on the content to see, with the wisdom in this room, if we have covered the major areas that we think we should, and then the Committee will take it on to craft them into that language.

The timeline for the overall report. Today, we will be talking about these draft recommendations. Between now and January, the Committee will be going back to the

drawing board. All the data has been collected, but we need to present it in a more readable format, with some interpretations. We're working on that. We will take suggestions today for the recommendations and put those into a language that makes sense.

That will result in what is called a "Public Consultation Report," which we will present here in February. That report is for your review and approval, and that report then goes for public comment. Again, you saw all of this process with the patents, and that happens in early Spring.

Next June, we will have a meeting like we had yesterday with patents, to go over the final recommendations, and that is the point where we will really be fine-tuning it. Then [we will] transmit it to the Secretary in July.

These draft report outlines, you're familiar with how they look, but just in quick summary, they always start with the executive summary and recommendations. That is the most important part, we've learned. The introduction has been written, and this is describing the scope of the problem, and some of the history of it.

Background literature is completed on all three groups, the education and training needs of all three of those groups that we outlined in the workgroups. Each group collected its own data, and that will be discussed in summary, and then the appendices will include all of the raw data.

The recommendations that we're going to be talking about emerged from a number of data sets, including what is in here. One was that we started off two years ago with a roundtable of experts. They gave us some suggestions about what areas need to be looked at. So that has informed the recommendations, the background literature that was conducted, as well as that original data that we collected.

One of our early tasks was to see what has been done, because there was a resolution written in 2004 from the SACGHS Committee, a different one, making some suggestions for increasing the genetic literacy. So we did go back and look and see what has been done in the last couple years, and there are some things to call out to.

One is, the CDC expanded its education mission to include health professionals and the public. We are

familiar with the "My Family Health Portrait" that is being widely used. NCHPEG has been very busy and productive, producing lots of educational products for specific groups and assessing the needs of various groups.

Between that time, the nurses have developed their own genetic certifications. The Genetic Counseling Workforce has increased, and soon there will be a series of articles in "Genomics," and "NEJM," I think early in the year, that addresses some of these issues specifically. So things are moving, but the Committee felt that there is still much work to be done.

Starting with the Healthcare Professionals Group, I'm going to highlight some of the key findings that were found from the literature review, and then the research for each group.

So first, the literature review regarding Healthcare Professionals. Just very generally, we found that integration of genetics into healthcare is limited by a lack of or inappropriate genetic education. The needs are dynamic, and they reflect career trajectory and level of training. So there is no such thing as professional education. It needs to be looked at in terms of basic

education, starting at basic training, advanced training for those wanting to go into specialty areas, and then continuing education for both of those groups. Different groups, different modes of education are needed, different needs.

The licensure, certification, and accreditation requirements have not kept up to date, and based on the American College of Medical Genetics data, there is an estimate that there is only 41 percent of the number of medical geneticists needed in the U.S. workforce.

This is a figure that gets quoted a lot and is very familiar to a lot of people, but I think it's important to sit in the larger context of the whole genetic workforce and look at it in terms of evidence that other professional groups', nurses and genetic counselors, physician assistants, numbers are growing. Their interest in genetics is growing, as well. So this figure of the 41 percent needs to be looked at within the larger context, even though it's the one that most people are familiar with.

In terms of the data collected by this group, there were two efforts. The first one was to survey the

federal agencies. One of the agendas was to see what changes happened between 2004 and 2009 or '10. We're going to be reporting on that data separately, so I won't talk too much about it right now, but the larger effort was devoted to surveying health professional organizations.

These were things like professional organizations, AMA, ANA, genetics organizations, educational organizations, certification groups, and things like that. They distributed 33 surveys and had a 58 percent survey return rate.

Very briefly, the findings. These reflect the overall tone. Of course, there are a lot more findings. There are pages and pages of findings. Among other things, we found that 70 percent of those respondents viewed genetic education as part of their role, but they see the need for more funding. More program evaluation also rises to the high [end] of their needs, and they find that if there is greater interest within their own organizations' leadership, that this will facilitate greater genetics education.

They report moderate proficiency and comfort, by their leadership, in genetics and genomics education. So

they feel like the leadership understands, but there needs to be more emphasis. Of course, competing priorities are a barrier to providing genetics and genomics education. That is a theme that we will hear time and time again.

The second group, the Public Health Providers Literature, suggests that the current public health workforce is not well prepared to receive and assimilate genetic and genomic information into public health. So they identified a gap.

Barriers that they identified are quite varied, including the diverse roles of the public health workforce, the various education and training path represented by that diverse group, out-of-date formal training, and a general sense within the workforce that the utility of genetics is not clear to them, how they're going to use it, why they need to learn more about this.

The data that this group collected resulted from a consensus process they followed to identify 12 competencies they thought were important for the public health workforce. These were then developed into a survey instrument and distributed to 500 individuals.

They got back a 133 responses, lots of responses.

This was a little interesting to do some numbers on this, because what happened is the survey would be distributed to one person in, say, a public health department, who would then look at it and say, well, I don't do genetics in this department, and forward it on to the two or three people they think do.

We lost control, very early on, of who received the survey, so we can't have good data on response rates, but we know who did fill out those surveys. It was an interesting and surprising process.

Some of their findings -- I'm just listing three of them here -- in terms of those 12 competencies, the one that was the highest rated was this one that read:

"Demonstration of basic knowledge of the role of genetics in the development of disease, and in screening and interventions for programs of disease prevention and health promotion."

Those of you who do surveys can see this is probably a double-barreled kind of question. So it's a little hard to interpret, but this was an overall one that got the highest endorsement. The lowest competency was in conducting outcome evaluations, similar to the Health

Professionals Group that felt this was the area of lack for them.

Two-thirds felt that the genomic resources were inadequate for implementing the competencies within whatever group they were part of.

Finally, the Consumers and Patient Group. Their literature found that the sources of information for consumers and patients are many, including the media, TV, a lot from the Internet, as we're learning about, and also from their healthcare providers. There is a sense, from many surveys, from their own self-assessment, and from others reporting on them, that the consumers generally recognized that genes and behavior are related to health outcomes.

So it's relevant information, but less is known about complex traits, and probably common diseases and multifactorial conditions. This was an area that was identified in the literature as consumers would need more education on if we're going to be looking forward to more research in that area.

Consumers expressed continued concern about confidentiality and disclosure of genetic information. I

think we're familiar with that, and most educational resources have been geared to those actively seeking information. These are people who go on the Web to look for a specific question or answer versus general consumers, general public who are just getting health information from many sources.

The data collected from this group started off with 11 semi-structured interviews with diverse individuals. These were people who were identified from the group as having some interest or expertise in genetics education among consumers, consumer advocates or people involved with those groups.

Based on analysis of those interviews, a survey was developed and administered on the Web to more than a thousand organizations, and these were considered "seekers of genetic information." This is a term that is used in the literature. These are people, again, who are actively looking for this information rather than passively receiving information about genetics. They had a great response rate of 300 individuals.

To supplement the fact that this was directed towards seekers of information, they then analyzed the

cogent consumer survey analysis, and this was a survey that was distributed to the general public, and cogent agencies shared their data with us. This group then integrated the analysis of that survey into their findings.

Some of their findings generally were that consumers often wish to get information about testing from primary care providers. This would be their preferred source of information, but they're not confident that those providers have adequate knowledge. So there is a little bit of unsettlement there.

The government is seen as a trusted source for information, and many consumers and patients felt that a role for the government was as a clearinghouse for information. Family history is seen as an important tool to understand health and disease. That message has made it through.

That is a quick overview of the findings. Again, you will see them in all their great glory in a few months, but we decided that we could go ahead and talk about recommendations before you see all of them, because this is an area we're all familiar with. There is nothing in the report that is going to shock you.

That is different than what we reported, and so we thought we would try to use this time to help us craft these in a way, as I said earlier, that we can move this field forward because it has been talked about for so long.

Now, a word about recommendations before I launch into them. People in this room have lots and lots of experience crafting and voting on recommendations, and know that any process that is searching for consensus is very iterative. When I say "iterative," I mean iterative in bold letters, very, very iterative.

One of the things that happens in that sort of process is that really good ideas can get lost in all the talking and consensus-building, and there can be a tendency for recommendations to drift to the midline. When I read our recommendations over, these draft ones today, I am alert to that possibility, that we may have drifted a little bit to the midline here and lost some in all of the deliberations that have happened over the months.

So I am calling on the whole group to help us make sure that we haven't left out some really great ideas that have come up at various meetings of the Task Force, and highlight those so that we can go back and craft them

into recommendations and try to get a little harder edge to some of our recommendations.

Generally, we can say, from the literature and from the data that we've collected, that there are challenges in achieving healthcare workforce genetic literacy, as well as within the other two groups. There is a strong sense, and I think complete agreement, that innovative approaches are going to be needed that tie efforts across disciplines so we're not just thinking about silos of health providers, and across layers of education, knowing that one individual's learning is lifetime learning.

So we should also think about ways to avoid that siloing of education into blocks, and these innovative methods may require public and private partnerships with federal and state government institutions.

Now, the needs of consumers and patients are not the same as healthcare workforce, but they also are going to require innovative approaches that take into account not only the new technologies that are available for education, such as social networking, things like that, but also the needs of diverse communities which we talked a lot about in

this community and the different learning styles of different communities as our population continues to get more and more diverse.

We're going to launch into it, and I think what I would like to do is read through them all and then talk about them at the end so you see them as a whole.

We have a total of 13, thank you, recommendations, so it's not a million. There are two or three that apply, or came out of each workgroup, and then there are two or three at the end that cross groups. I am going to go through all of them first.

The first one came out of the Health Professionals Group, and it talks about integration and the recommendation is HHS should encourage the integration of genetics and genomic content into all levels of health professional education and training programs relevant to the needs as identified by specialty groups. That last phrase is thought to be important, that the needs would be identified by the groups rather than from above.

This is obviously a broad recommendation and is kind of speaking out to the levels of education and speaks a little bit to academic curriculum and clinical practice

settings.

The second one is similar but has more of a healthcare delivery tone to it. See if it's distinct enough. Should fund multidisciplinary public/private genomics/genetics education advisory panels whose function it is to prepare a model framework for education, licensure, accreditation, and certification requirements in preparing a personalized genomic healthcare, dah-dah-dah. So that has more of a delivery tone to it.

The third one, again reflecting healthcare professionals, is speaking to interdisciplinary collaboration. HHS should support formal and informal genetics knowledge sharing by facilitating interdisciplinary collaborations.

Now here we're acknowledging that these collaborations are much more practical in large settings and, indeed, often happen in large settings but is more problematic in rural areas. So there's a call-out in rural and underserved areas. Should employ innovative technologies, such as telemedicine conferencing, to share knowledge and expertise again across disciplines. Then acknowledging that there are barriers to this,

reimbursement is one, added another notion that should encourage reimbursement for these interdisciplinary teams as well as for these distant consultations that we just referred to in the rural area.

The public health providers, the first one, is to assess the size and scope of the public health workforce that have genetic and genomic responsibilities to ascertain current trends and plan for future needs.

We know that public health providers are a very divergent and -- I shouldn't say divergent, diverse. They are the nicest people. They are not divergent, and heterogenous workforce, and their role is likely to change with any sort of healthcare reform we may be getting. So it may be very timely to conduct a systematic assessment of where they are, who they are, and what they're doing.

The other issue around the size of the workforce is whether the numbers are keeping track with the future needs, particularly in the genetic workforce area.

Because that group dealt with competencies, this one makes sense. HHS should facilitate the development of relevant core competencies for all federal and non-federal public health providers and specific competencies for those

whose role requires such knowledge.

So this is speaking to the reality that there are some public health providers out there whose job responsibilities require very explicit genetic knowledge and competencies. Now others require just basic knowledge and we're trying to distinguish between the two and not distinguish between the two.

So this recommendation is responding and referring to two quite different groups within the public health workforce. Embedded in this is the reality of competing demands that are always in there for all these kinds of health professionals.

Next one is similar to the interdisciplinary practice of the earlier group, is collaborative training, and this one is suggesting that there be promotion of collaboration for genetics/genomics education and training between medical and public health professionals to benefit population health and as an example, schools of public health and medical schools and AMA and APHA.

This is referring to the traditional schism between medicine and public health and seeing if we can narrow that schism at least in this area of genetics and

the importance of doing so.

Recommendations that came out of the Consumer Group are first to improve genetic literacy. Efforts to improve literacy of consumers and patients should be based on educational theory and be coordinated with other federal departments and agencies and community-based organizations.

A question here is whether or not to include language about K-12 or K-college education. This was decided very clearly as outside of the scope of this task force, K-12 education, but a lot of the suggestions that came from consumers is to have a literate adult consumer population, the education needs to start earlier. So it's really hard to draw that line in the sand to say where education should start. So that was one area we grappled with.

The next one is about resources. They should support the continued and expanded development of education resources to enhance the public literacy. This one, embedded in here is the idea, is the need for creative resources to match how people are getting information currently, and again we've talked about those methods, it's pretty exciting now, but also again always with this to not

lose sight that there's some of under-served and ethnic communities that use other sources of information, such as ethnic media and things like that, and that their needs must also be met. So we shouldn't go down the path of getting all excited about high-tech educational resources and lose the fact that this is a very -- it's only one segment of the population that accesses that, though it's a very interesting and growing area.

Family history. HHS should support continued efforts to publicize the importance of family history, ensure access to tools in various formats and inform consumers about the importance of sharing this information with primary care providers.

This one may stand out a little bit, but in thinking about priorities, what came out of a lot of the literature and the recommendations from the Consumer Group and Patient Group was if there was one thing that you could teach consumers, what is the highest priority area, what do most people feel would be the biggest bang for your buck, family history sort of rose to the top of that.

This is about genetic research. Should inform the public about their risks and benefits of participating

in genetic research through national and local efforts. This is really calling out to the committee that was just formed, I think the Genetic Data Sharing Committee, whatever the name of it's going to be, Charmaine's committee, and I think we just talked about that last month, so that one's pretty self-evident, I think.

A couple recommendations apply across the group and this next one, Number 11, is a whopper. In consultation with several agencies, HHS should ensure funding of a national strategic planning mechanism for genetic and genomic education and training of the healthcare workforce.

This planning group should include various individuals we often don't include on these governmental groups, individuals who are experts in the content and the educational needs of specific disciplines and experts outside of these traditional fields who are innovative thinkers regarding the incorporation and adoption of knowledge in a technology-explosive area while looking toward the future in genomics education.

So I'll leave it at that and say this is a large recommendation, but the tone of it, you can see, is to

let's try something different. Let's form a group that maybe hasn't been formed before and pull together people who aren't usually sitting at the same table.

Next one is about faculty training and it crosses all groups because faculty, healthcare professional faculty as well as public health provider faculty, due to the identified shortage of clinical and public health educators with formal training in genetics, HHS should facilitate increased training for academic healthcare educators and an example is provided through HRSA training grants but there's other mechanisms.

Translation, of course, crosses all groups, should support research and assessment on development of effective methods for translating science to healthcare professionals, public health providers, and consumers and patients.

This one might be seen or interpreted as a call for the redistribution of funds from basic science to translation science and that's it on the recommendations.

We also need to do a shout-out to prior SACGHS reports that address the educational needs and this is an area that was identified from the first SACGT meeting as a

priority. So there's lots of reports that talked about it. As a matter of fact, almost every report that comes out of this group has one bullet point to increase genetic education and training among somebody.

So the three that we identified so clearly were the coverage and reimbursement report, oversight, and pharmacogenomics, and they all talk about education from different perspectives and we're sort of pulling together the specific recommendations from those to highlight those, and they're in the folder.

Okay. I think we have like about a half hour, something like that.

#### **Committee Discussion of Draft Recommendations**

DR. TEUTSCH: Yes. We have a half hour.

DR. McGRATH: Great.

DR. TEUTSCH: And as Barbara said, I think the important part is to go over these recommendations. How do we make them sharper, more actionable? I think, clearly, we make our recommendations to the Secretary. Some of these also talk about other groups that might do them, but I think we need to think about how we do those so that we get them addressed to both audiences.

But, Barbara, I would welcome that. It looks like you've got some, and Jim.

DR. McGRATH: Jim.

DR. EVANS: Great. So, Barbara, first of all, congratulations. This is a huge task and I know I've been rather preoccupied at patents but hopefully can reintegrate here.

One of the things I wanted to mention that might have gotten a little bit lost is -- two things. One is a discrete suggestion, the other is more nebulous.

In Recommendation 2, as somebody who teaches students and who teaches residents, I'm acutely aware of the fact that the formal didactic mechanisms we have for teaching are woefully inadequate and people forget these things and I think it might be useful to have a sub-bullet or something along these lines.

Genomic education should be directly integrated into patient care when clinically useful and necessary to get at the issue of like just-in-time-type things. I think that when you look at the competing priorities that clinicians have, they very understandably don't do as much didactic stuff as we would like. That's a way of not only

getting them educated at the right time when the patient will benefit, it also might be a way, and this leads into my nebulous comment, of addressing the fact that we do want to emphasize this education when it has been shown to be clinically useful.

I think that we can be easily criticized if we're not careful for trying to kind of sell genetics to the rest of medicine and when you look at the important comment on Slide 11 where one of the barriers is, a general sense of the utility of genetics is not clear to public health providers at this time, I think the same can be said for clinicians and it's valid, right.

We need to make sure we are advocating education when it is clinically useful and not just to promote our own kind of --

DR. McGRATH: Can I think ask a follow-up question back to you? So the first one is about curriculum?

DR. EVANS: It is. I just don't like the word "curriculum" because what it evokes is the idea of sitting in class or sitting and taking a course.

What I would like to see is some emphasis that

says how can we integrate this curriculum, if you will, into the practice of medicine where applicable, where useful.

DR. McGRATH: Right. And that's what I meant when I said curriculum. So this group and the Secretary of Health and Human Services, what is her role? What are we directly asking her to do with trying to take healthcare professionals' curriculum training to a different level to respond to that?

DR. EVANS: Yes. Other than saying we're asking her in that context to do the same thing that we would in all these other contexts, which are more didactic in their emphasis, I'm not sure.

DR. McGRATH: Okay. All right. Sam.

DR. NUSSBAUM: Barbara, I think these are a absolutely terrific set of broadly encompassing recommendations and to your point of making them more actionable and actually, Jim, building on yours of making these relevant, there's a whole process that's going forward in professional organizations of recertification and I know it's happening certainly in medicine, nursing professionals and others, and so one way of getting there

is to actually encourage building these into the very real practice improvement modules. They're called PIMs, the American Board of Internal Medicine and others, and the way that this could be really focused is by recommending to the Secretary that she look at ways, innovative ways of reimbursement.

So, for example, if you successfully complete recertification with genetics and other training modules that you might even have as a composite, getting greater reimbursement for primary care and other areas. So I think it can be directly applicable through reimbursement as an incentive for those organizations to include these as learning laboratories.

I know it's in the detail, but I think unless those are built in, there will be so many competing activities, and I think, while you can begin to focus in the current curriculum for undergraduate education and graduate education, there's so much lifelong learning that needs to take place in the field that's rapidly advancing, this might be one of the ways of facilitating that.

DR. McGRATH: That's an interesting idea.

Thanks.

DR. AMOS: I just have one of these silly naive questions that I always ask. I just was curious. I mean how do insurance companies get their information? I mean in the spirit of healthcare reform and that's what everybody's talking about, I mean, I know they have people that do that, but is there a role for HHS to interact closer with the private insurance companies to provide them with better, more useful information, considering the fact that reimbursement does drive adoption?

DR. McGRATH: That's a group, when we first were tasked with what groups, what our focus should be, that was a group that was called out as well as healthcare administrators, clergy, judges, various other groups that we know have a very important role in all of this, but we did have to draw a line in the sand some place and say that's for the next task force to do.

So I don't know how to answer that question, how they get their information. I guess we all sort know how they do, but I don't think that's within the purview of us looking at that here, though. It certainly absolutely has an impact and we do have a paragraph written about that we define the group this way, but we recognize that other

groups have an impact on all of these topics. That would be one I would say.

MS. LLOYD-PURYEAR: The Secretary's Advisory Committee on Heritable Disorders is also sending forward a recommendation concerning primary care education specifically. They focus on primary care providers since those providers are pivotal in educating about newborn screening.

I would be glad to share that recommendation. It is very specific.

DR. McGRATH: Thank you. That'd be perfect. We need that.

Sheila.

MS. WALCOFF: I was just going to follow on to Sam's comment, and I would say if we're going to suggest any funding, I think that trying to integrate into the resource use some sorts of incentives is a really good idea rather than funding more committees because I think there's an opportunity to tuck some of that stuff into existing work that's already being done at CDC and other agencies and then look for more specific ways to directly impact the objective of the recommendation. So I think that's a good

idea.

I don't know exactly how that would be done, but since there's so much debate and discussion going on, particularly depending on how health reform works itself out, that there might be some opportunities to incorporate some incentives in that regard as those are being redeveloped under new provisions that might be enacted.

DR. McGRATH: Muin.

DR. KHOURY: Barbara, first, I would like to compliment you for all the hard work that all three groups have done and your leadership in this. I know I've been dropping in and out of the Public Health Group and just to see it in total, I guess it's sort of a lot of stuff in here.

I'm wondering, I mean I want to echo two things that I've heard from Jim Evans, from Michele and others, and also my own kind of agency-centric view, that when I get this at the end because I'm part of HHS, what will I do that I'm not doing now? That's sort of what I'm thinking.

So, for example, Number 5, develop core competencies for public health providers. I think we've done that seven years ago. Are you directing me to do

something that I didn't do? So, I mean, we have to be a bit more specific.

Assessing the public health workforce. That's Number 4. It's very crucial actually because, I mean, as you mentioned, Barbara, the heterogeneity of the public health workforce and their various needs, I mean, we have state epidemiologists who do disease outbreak investigations. Their needs for training in genetics are very different from the educators and the administrators or the environmental health specialists or whatever, and we've tried to come up with that assessment over the years, although it's been incomplete. It's very hard.

The workforce is shifting and maybe we should work on this between now and January so that when we come back, those recommendations have to be a bit more crisp and rather than sort of like broad brush develop core competencies. I think that's good, but tell us more. I would like to see if we can do that together.

I like these creative multidisciplinary advisory panels, although I have no idea what it means, for healthcare professionals, but I suspect that it will be cross-cutting, involves public health and consumers, that

Number 2, and maybe someone from that group can explain what that means a little bit more to me.

One additional comment on public understanding of genetic research, Number 10. I think we need more than just public understanding of genetic research. I think the word "understanding" implies that they are very passive recipients of information and what we need is more public involvement, public understanding in the way that they own the stuff, it's their genome, and maybe I'm looking for a different word.

So I think this is great stuff here. I like the focus on family history because, as part of my public health adventures over the last 10 years, everywhere I went, people kept telling me, well, you have nothing to sell, except family history, which 10 years later I say, okay, okay, we'll sell that to you, but that's fine. So it's a good thing.

So, I mean, forgive me for my wide-ranging musings right now, but I think this is the beginning of something that could be focused, targeted, and by putting the three together, I think we're going to find more points of synergy, and coming back to Michele's earlier point

about providers and primary care, because, I mean, the healthcare providers are not all the same and I think talking to the specialists is one thing who are more in tune with genetics, but the primary care providers are more like public health professionals or more like lay audiences in some sense, and I think those need to be pieced out of the healthcare professional morass and dealt with in a much more comprehensive way.

Thank you.

DR. McGRATH: Thanks. I would like to follow up on a couple of those, just the last one. The emphasis of the first group was really on primary care providers, although there is some data on specialists, but we've followed that suggestion. So we're really looking at sort of point of care as how we define that group. So it is heavily a primary care orientation.

But I wanted to follow up on the idea of the panels, advisory panels or groups kind of in response also to Sheila's comment, but before that, Sylvia, I wondered whether you could help us understand the point that Muin just made on the core competencies, that they have already been done seven years ago.

Is there something different that you think needs to be done in terms of core competencies for the public health workforce around genetic competencies?

MS. AU: I don't think something different needs to be done and, yes, I think that it just pretty much reinforced that those were the same competencies that the public health workforce needed. It's just that when they were done then, nothing happened. We've just reinforced that they still need to be done and maybe our recommendation needs to be what we should be doing or how we should be moving this forward because obviously it's been seven years.

We've reinforced that the competencies are still relevant, except we've condensed them down to 12.

DR. KHOURY: Maybe you can sharpen the recommendation, rather than just developing but more applying, recommending.

MS. AU: We can sharpen the recommendation.

DR. McGRATH: That's perfect. Thanks for that.  
Marc.

DR. WILLIAMS: I just wanted to make specific and hopefully tie together some of the comments that have been

made.

In my view, the most important aspect of what we're putting forward here is to try and get outside of the traditional educational thinking box and really figure out how to do something innovative because, as I view this, not being a professional educator, the real disconnect is that we seem to have this, as Jim might phrase it, this curriculum that we present at some point for a certain amount of time to our various groups, whether they be public health professionals or physicians or other providers, and then we say go forth and be knowledgeable and then when they encounter the clinical world, whether it's as a third year medical student or as a public health person doing an internship or whatever, they get no exposure to it because the generation of folks that are out there in practice aren't incorporating that in their practice and we know that it's that type of modeling when you're actually in the clinical environment that actually builds your life-long practice patterns.

And so it's really an idea of how do we -- one could argue that perhaps this is just something that will fix itself in 20 years because, just as we have now a group

of physician trainees that are coming in that are very computer savvy, so we think that the electronic health record problem will probably get better as they get into practice, maybe this will be the same issue, but I would argue that that's a gap that's probably not reasonable to allow to happen.

So how do we get this into that clinical training so that people can see the relevance of this for those purposes where we do have good evidence so they can begin to think about it and then, once they're in a post-training environment, how can we leverage the things that we're now developing through the electronic health records and that, so that we can provide information to them that they can incorporate on a regular basis?

You know, for me, of all the recommendations, it's trying to develop a group that is going to have a very different perspective and take a very different approach to this because I think we are suffering from the thing. We've been talking about this for a very long time, yet arguably we haven't made any progress, and as Einstein said, you know, a definition of insanity is doing the same things over and over again expecting different results.

DR. McGRATH: That came through so strongly throughout all of these. The hard thing is how because what you've just outlined is you've got different organizations. Primary care providers are lots of disciplines. You've got undergraduate training. You've got clinical training. You've got postgraduate training and then you've got licensure certification. So you've got lots of bodies involved and so one suggestion, I think that big one at the end is talking about forming the walking on water advisory board.

Is that the best way to implement change, to push ideas like that forward? I don't know how to, beyond saying this should happen; what is the way.

DR. WILLIAMS: Well, I think the other thing that could potentially be under the Secretary's discretion would be inasmuch as there are some monies that are directed towards evaluating health professional education, that if we could develop some -- I think this is an area that in the innovation world would be described as needing slack resources and what I mean by that is that you need to have a place where innovators can take nutty ideas and try them out and the problem is, is that when we run nutty ideas

through a traditional vetting process, everybody says that's a nutty idea, we're not going to fund that.

So we need to have some space and have some resources where people can really explore dramatically unconventional ways to do this, expecting that there's going to be a relatively high failure rate, but that there may in fact be a few things that emerge from that that are really quite unique and important, and at least in industry, that type of a model is a great germination field for innovation, but it's something that we don't have the room to do for the most part. We don't have room in most curricula to be able to set aside a space for craziness.

DR. McGRATH: Thanks. Be way fun. David.

DR. DALE: I'll just make one comment. There's a very good group that's, I think, engaged through the Institute of Medicine and some other sponsors in health literacy where they have tried to tease apart the levels of education and the specifics for helping people to understand their prescription bottle or the specific terms related to their illness, acknowledging the low general level of education of our population, and I think it would be a practical suggestion to engage with them in terms of

where are we and what do people know if you say DNA and so on.

The other comment I would make in follow-up to Marc is I think it would be constructive to encourage the Secretary to engage in defining areas of success and education of practitioners as modeling for success.

An example would be anti-coagulation for people with atrial fibrillation. That's become a standard of practice and another would be beta blockers after myocardial infarction, a standard of practice. So many organizations try to achieve high levels of compliance with those specific recommendations. So that's guidelines at a high level that can be taken forward in terms of practice evaluation.

And to dig deeper is to encourage the Secretary to provide the funds and the modeling to find the specific ways, as Jim points out, where it makes a difference.

DR. McGRATH: Great suggestion. Julio.

DR. LICINIO: I just have a comment that ties with what is being discussed here with what was discussed before, that some years back, I did a whole bunch of community engagement in L.A. with Mexican Americans and one

thing that came out that became very obvious and actually I had to be funded for that eventually is that it's very hard to engage a community in an area that they know nothing about.

So it's necessary to really do education and training in parallel with engagement because, yes, it can take a very like ethnograph position and say like what do they understand, what do they want to know, what the questions are, but if they really don't have the background knowledge, the engagement process is very difficult.

So I think that there could be some effort to tie the two things together, especially since we are discussing them both here, but establish some kind of connection between the two.

DR. McGRATH: Rochelle.

MS. DREYFUSS: Thank you. I'm sure it's widely naive, but just to follow up on Julio's question.

DR. McGRATH: I doubt it.

MS. DREYFUSS: I think for a large segment of the population, what they know about DNA is forensic DNA. I mean, they know they might be identified as a suspect in a crime, and I wonder if there's any way to build on some of

the things that they do in the juvenile justice system to help bring more understanding of genetics to young people.

DR. McGRATH: I know there's a lot of talk about the CSI knowledge that a lot of people are getting. We've been talking about that.

Do you want to address this? Okay. Great.

Michele.

MS. LLOYD-PURYEAR: Well, actually, you bring up, I think, a very important point about genetics education in general, and I think an analogy could be HIV/AIDS education.

The government did make a big effort during that time period to focus on health profession and public education around HIV/AIDS, but the key here was that it had to be -- it was needed, that knowledge was needed. It was being incorporated into every-day practice. It was a need for the public to understand and so your point about focusing on something that's tangible, that can be used, I think, is very important, and I think, with the recommendations, and it goes back to what Muin, I think, was saying, what are you asking anyone to do right now? Is genetics or genomics ready to be used by primary care

providers? Is that perhaps the problem?

When we, with NIH and AHRQ, began the Genetics in Primary Care Project in 1999, there was a great deal of enthusiasm, but what was wrong with it is that there was nothing that -- very little primary care providers could do with that knowledge in every-day practice, and I think that's still an issue and my advice actually would be to focus on public education, that is a big gap, and family history, I mean really to go out towards that area because it's tangible and it is part of every-day practice.

DR. McGRATH: I think you're responding to something that we found in the literature as well as from our surveys, is that there's a question about how much does the public need to know, and if you divide them into two groups, seekers of knowledge, if you have a condition or for some reason you're interested in something, there's access for that. People are getting that on the Internet. They can go to their provider, if they have one, or whatever.

But the other question is what does the public know and is it even important for the public to understand DNA structure and GWAS studies or is it more the downstream

how that is going to affect them and that's why family history rose to the top. Is that something that people can do something with right away?

Sort of following on the idea that lots of us follow practices without understanding the science of it. Most people take their cholesterol drugs aren't really understanding exactly the whole notion of plaque formation. Does that matter or is it just more important for them to know their family history of cardiovascular disease and medication adherence?

So it's kind of an interesting question about we may want people to know lots of genetic information but competing for their attention about what is important for them in terms of public health, we have to be sort of wise about that, as well.

I was actually going to ask -- I saw Vence here earlier. Oh, there he is, hiding. Whether you wanted to speak to that notion of the public's literacy and that boundary of not being geno-centric but also recognizing there's a need for education as well as engagement.

DR. BONHAM: Thank you. I think the key issue that was raised through the data that we gathered was the

need to be able to be informed to make good decisions and asking the right questions, not having a foundation, as stated by Barbara, around the specific types of technologies but to be able to make informed decisions when you're at a time when you need information and the distinction that we did see between those that were seeking information, either because there was a genetic condition within their family or making decisions with regards to participating in direct-to-consumer genetic testing, and those that are the general public when they do need information, that they have enough knowledge to be able to ask the right questions and to seek out the information at that point in time.

DR. McGRATH: Perfect. I guess one more question. Thanks.

DR. AMOS: I just have a comment. I take my professional hat off and looking at all the information that comes out in the newspaper and in the popular press and every day, especially over the last three or four years, there's been this new gene that's been discovered and it's like drinking from a fire hose because all this information is coming out but yet it's so vague and where

is it really going to happen and every report, it's like, oh, you know, the possible cure for this and possible cure for that.

So I would really support the role of HHS as providing a real clearinghouse. It's very, very confusing for anyone, I think, to really understand the utility of this and certainly for families who have got genetic disorders or illness in their family, the resources are available and they're critical, but what is it live and Memorex? What should anybody be paying attention to is the critical question.

DR. GUTTMACHER: I would just like to pick up on the theme that Michele and some other people have been talking about, about the relative importance perhaps of public education versus professional education.

I have NHRI and I have personally been involved over the last decade in lots of different kinds of education in my field. We're equal opportunity education attempters or something, but I must say that I over the years have grown more and more of the view that health professions are such a practical lot. Give me something I can use tomorrow, I'm going to learn to use it.

Clearly, what we're trying to do here, and I think it's an important effort, is to make sure that we don't waste this window of opportunity when we see these tools are about to arrive so that when they really do arrive, people are ready to use them, but there's only so much that can be done there.

I think efforts, like NCHPEG's efforts, I think, were wonderful. We should do everything we can to encourage and support those, et cetera. At the same time, I really do think it's the public education and creating greater genetic literacy across the landscape that's important.

I think of all the education efforts we've been involved in over the last decade. Probably if I had to choose one that I think is the most significant, it probably is really the Surgeon General's Family History Initiative and that web-based tool that lots of people in the room, Greg Downing particularly in the last few years, have been involved in furthering, that and electronic health records, et cetera.

But family history really does have a role for, I think, bringing the public into this. In some ways, I

think to tackle this question, I would even provocatively say I guess we're advising the wrong Secretary, that the agency that doesn't appear in this report that maybe we should think about encouraging the Secretary to talk to is the Department of Education, that if we really want to educate the public broadly about anything, how do you do that? You do it through the public school system in the United States, and there have been some inroads there, but I don't think we've paid nearly -- the genetics community, all of us, I'll make myself personally responsible here, we've not paid enough attention I think to that venue in some ways.

If we really want to try to educate the public broadly, that's the place to go, and we probably should be increasing efforts. Something new that this committee could, I think, help focus things on, everything that's in this, it's hard to argue against any of the mom and apple pie that's in here, but in terms of making some new added value, that might be a direction that we would want to encourage.

DR. McGRATH: Gwen, do you have one? And then I think we're done.

MS. DARIEN: I have something very quick to say which builds on Rochelle's comment and also builds on what we said yesterday about GINA and the fear of the infringement of privacy, not being able to find a lot of privacy, and I think one of the issues we have to think about when we think about educating the public is the public's fear of what genetics will do and their association of DNA and all of this science with criminology through the media and so I think that that's something just to be aware of when we frame all of this because I think people -- I think that their DNA or their genetic information is going to be taken and used to do something that is detrimental to them, whether it's from a criminal standpoint or whether it's from a discrimination standpoint.

DR. McGRATH: Right. Well taken.

DR. BONHAM: Alan, the committee, the Public Education Consumers Committee, specifically stated that that would be extremely important if we could reach out to other Secretaries and to other agencies around genetics education for the public.

DR. TEUTSCH: Great. Lot of important

information. I think some of the things I think we are going to need to take home is make sure that everybody understands what the real need and what the real opportunities are at this point in time for genetics and how it fits in against all of those competing needs.

One thing I didn't hear from this discussion but builds on sort of how do you get information out and get it actionable gets back to the electronic medical record and the clinical decision support thing, to get people the information when they need it, and they need to have the skills to be able to understand that, but it's all part of the quality improvement processes that we've talked about, too.

So I think as we go through this report, I would like to see as clear an assessment as we can of what are the impacts of these recommendations because they're very broad and sometimes the priorities so that we can begin to help the Secretary make some choices which of these are likely to be most impactful and bring in the ex-officio members from education would be really helpful in this process because I think we've heard that they're going to be an important player in all of this.

So thank you, Barbara, for all your work and all your committee's work and we'll look forward to going through these in detail at the next meeting.