Discussion of Draft Education Resolution
Full Committee

DR. McCABE: We're going to consider the draft resolution on genetics education and training of health professionals. This can be found at Tab 4 of your briefing book, and staff has also put it up on the screen here. Joan, are you ready? I didn't check with you. I'm going to turn it over to you for this discussion of the education resolution, or we can do a tag team so we can both eat, if you'd like to do that.

DR. REEDE: Why don't we tag while I chew?

DR. McCABE: Okay. So I'll start off, and then Joan will take over. You have the draft resolution up before you. Somebody commented that it sounded a bit stilted to have all the whereas', but unfortunately, that is the nature of resolutions, to have all those whereas', so I think we're stuck with those.

So, "Whereas the Secretary's Advisory Committee on Genetics, Health, and Society was established to advise the Secretary of Health and Human Services on the range of complex and sensitive medical, ethical, legal, and social issues raised by new technological developments in human genetics."

I know it has been brought up about family history being the first genetic test. I think that a couple of the ex officios were looking at where we might fit family history into this. Any comments? Alan, were you one of the ones working on that?

DR. GUTTMACHER: I wasn't working specifically on a place to put it, but I think there were a number of us that thought it should be put somewhere.

DR. McCABE: Okay.

DR. GUTTMACHER: But I will pay attention now while we work over lunch as to where it should be put, unless somebody else has a good idea.

DR. McCABE: We could certainly work on including it in the recommendations, if we didn't want to insert it in the whereas.

DR. GUTTMACHER: And I would think it would make more sense as a recommendation, rather than a whereas.

DR. McCABE: Robinsue?

DR. FROHBOESE: I do have a specific recommendation. I think in keeping with the very good recommendation that Reed first came up with, and then others supported in linking with the Secretary's efforts on health information technology, and the fact that that could be one place where we can include family information, I think in recommendation Number 1 which already addresses departmental policies and programs about genetic information, that there we specifically include family history, and a recommendation that the CAHIT effort in the Department on health information technology include looking at genetic information and family history as part of its overall recommendations in formulating an action plan.

DR. McCABE: Okay. Joan, are you ready to take over?

DR. REEDE: Sure. Moving forward, any other comments on incorporation of something related to family history and looking at inclusion of information technology, looking at genetics and family history within recommendation one?

DR. KHOURY: Maybe this was said earlier. But I guess anytime we use the word "genetic information," we can put slash, family history to it, because family history is much more than genetics. It represents shared environment, shared cultures, and shared behavior.

So the philosophy that genetic information and family history should not be exceptional and so on and so forth, you know, search for the word genetic information in family history.

DR. REEDE: Martin?

MR. DANNENFELSER: I guess I just wondered, in the context of the

Genetic Information Nondiscrimination Act, is this covered information within that, or not? Obviously if you have information in a medical record relating to preexisting conditions, that can be problematic, I imagine, to a person in terms of health insurance coverage, or potentially employment. Does putting family history in there have any impact on whether or not that is protected information within the context of the Genetic Information Nondiscrimination Act?

DR. REEDE: Any comments?

MR. GRAY: Well, the bill, as passed by the Senate, defines genetic information to include family medical history. It is specifically included in that, and I think it is important that we recognize family medical history is a part of genetic information. I would certainly make the point.

DR. REEDE: Any other comments with regard to this family history and information technology in recommendation one?

DR. FROHBOESE: I was just going to add that by including it in that first recommendation, and in the context of the Secretary's Health Information Technology effort, a critical part of what that group is doing is looking at privacy, confidentiality, and nondiscrimination. The Office for Civil Rights is an active participant in that, and is ensuring that the privacy rule under HIPAA and nondiscrimination considerations are part of the formulation.

So I think by putting it in that first recommendation, we'll have some assurances that those considerations will be part of formulating any recommendations.

MR. GRAY: Can I just make one suggestion? The way it is written now, it says, "genetic information, including family medical history information." I would just change that to say, "which includes family history information."

The reason for that is that I want to make sure it is clear that family medical history is a part of genetic information, that is not something that is separate.

DR. REEDE: Moving on, the next whereas is, "Advances in genomics have the potential to greatly improve health status and outcomes," and "Appropriate and adequate training and education in genomics is crucial for all health professionals to assure the successful integration of genomic concepts and genetic technologies, and services throughout the entire health care system."

DR. LEONARD: Maybe we should add to that, "Whereas health professionals and the public." Because we have been bringing up over and over again that the public is an active part of this process, and so their education is just as important as the health professionals, in a different way.

DR. REEDE: Any other comments?

MS. HARRISON: Joan? I would advocate that we make that a separate whereas, because I think the adequate training and education in genomics, obviously we're meaning a different type of training and education. So I very much advocate for the public education piece to be in the whereas, but I think it should be separate.

DR. REEDE: Any other specific comments with regard to the public education piece? I think there was actually a very rich discussion at the end about the need for the public education. It seems clear that it should be incorporated here somewhere in terms of a separate whereas, or an integration into these current ones. Any thoughts?

DR. WINN-DEEN: I think it is important to include sort of the public education and capture this concept as an informed consumer, that we need them to be educated so that they can be informed consumers, and active participants in their health care.

DR. FEETHAM: For the previous one, to be consistent with the language from Muin's comments, and Toby Citrin's comments of saying health care and public health professionals in your prior whereas, and look at that throughout the document.

DR. REEDE: So in this area, and any other area?

DR. FEETHAM: Pardon?

DR. REEDE: So in this section, but in any other areas, making it more

broad?

DR. FEETHAM: Right. Saying health care and public health professionals, I think you'll cover a broader scope.

DR. REEDE: The recommendation here was to, "Engage other health professionals, the private sector and colleagues at the federal and state levels to facilitate the cataloging and dissemination of genomics applications to clinical medicine and public health, and models based upon these applications to ensure genomics has impact now, as opposed to far-off in the future." Emily?

DR. WINN-DEEN: I just want to say I think before we move down to number two, that we should probably split one into two different things. One is sort of including genetic stuff and Department policies, and then the second part of that is talking about education. Then I think two becomes three then, if we do that. It just seems like one now has sort of two different thoughts in it.

DR. REEDE: So one relates to departmental policy, and the other one relates to overall education and training. Okay.

MS. CARR: And where would you see the point about family history? Would that be part of the second one, then? Or a separate one altogether?

DR. WINN-DEEN: I think the family history, it needs to be integrated as part of the training and education of health professionals to take family history, and to make it part of medical records. I think it is appropriate, sort of the way you have split it there.

MS. CARR: Okay.

DR. REEDE: Look at recommendation Number 2.

DR. LEONARD: And so two should start with "Integrate genomics into the education." So it is like the other ones.

DR. TUCKSON: (Inaudible.)

DR. McCABE: Reed, we're not hearing you. You'll need to speak up.

DR. TUCKSON: The third whereas. Can you hear me now?

DR. REEDE: Yes.

DR. McCABE: Reed? It sounds like you are a little bit close to the mike.

DR. TUCKSON: How about now?

DR. McCABE: That seems a little bit better.

DR. TUCKSON: (Inaudible.)

DR. McCABE: You're breaking up.

DR. TUCKSON: I'm breaking up now?

DR. McCABE: And we aren't trying to ignore you by saying that.

DR. TUCKSON: All right. I'll try to call on a different line.

DR. McCABE: No, that's better.

DR. TUCKSON: Okay. The third whereas --

DR. REEDE: I beg your pardon?

DR. TUCKSON: I heard you a moment ago about the third whereas (inaudible.)

DR. REEDE: Right.

DR. TUCKSON: Have you completed that discussion?

DR. REEDE: No, I don't believe we have. We talked about the addition of the public, and putting it within this whereas, or creating a separate whereas that refers to the need for public education and training.

DR. TUCKSON: I'd like to urge a little bit of (inaudible) integration, add a little bit of that to the discussion.

DR. REEDE: No, it hasn't. So you're speaking specifically to the word "successful" and another word that might be more suitable?

DR. TUCKSON: Yes, and I'm not sure what successful means. And so I'm

thinking of appropriate, effective, and efficient integration.

DR. REEDE: Appropriate is what we have up there now.

DR. TUCKSON: Appropriate, effective, and efficient.

DR. REEDE: Is there any further discussion around incorporation of the public within this, or setting up a separate whereas for public education?

DR. FELIX-AARON: I think as a standalone whereas, I think it is very effective. The only other thing you may want to consider is to add a phrase at the end. It could say, "Whereas appropriate education and genomics is crucial for the general public to reap the benefits of, or to take advantage of the power of this." So that it clearly specifies that not only the public needs to be engaged to be better consumers, but also for them to get the benefits of this vast technology.

DR. REEDE: Okay. The next whereas was "Whereas such integration is a necessary component of access."

MS. CARR: Dr. Reede, can I just go back to the one prior to the general public? The last part of that read, "the entire health care system," and we had a suggestion that it just read "the entire health system," that that might broaden it a bit. Is that okay?

DR. LEONARD: In the second whereas, I guess it is, the third whereas, we were going to add public health and health professionals, or we were going to broaden that to be public health and health professionals.

DR. FEETHAM: The language that we used in a lot of our documents through HRSA and NIH is health care and public health professionals.

DR. REEDE: Brad?

MR. MARGUS: I have another whereas to talk about. Are we ready for another whereas, or do we have to finish that whereas? Going to my question about what was broken, and Mr. Citrin's response to it, I was thinking that this might sound a little negative, but it would still underscore maybe an urgency to do something.

Something along the lines of, "Whereas insufficient training and education can lead to excessive costs incurred on inappropriate tests," since he brought that up, "inaccurate, or at least illusive disease diagnoses," which is what we just talked about, "and in many cases, misguided disease management and family planning." Those are all negative things that can come about if the Secretary doesn't do anything about this.

DR. REEDE: Sort of in this area, the broken things, the issues that created urgency. Are there others that you would want to add to that list?

DR. WINN-DEEN: Yes. When Sarah gets done typing this list, and I'm just going to comment that I don't think the excessive costs should be the first thing. I think the first thing should be the patient management issue. Obviously costs are important, but I think the key thing is that patients are not being managed as they should be for their medical condition.

DR. FEETHAM: Another concept of that lack of education is access, in addition to the patient management.

MS. BERRY: We'll probably have to reorder them, won't we? Because when it says, "such integration," it refers to the two other whereas' above.

DR. REEDE: What you said is education is a necessary component of access. I was wondering if you wanted to say something more specific about genetics.

MS. ZELLMER: On the whereas as far as where it says, "Such integration is a necessary component of access," which should refer to the third one, I think actually access is affected by education of not only the health care professional, but the public. So maybe we could just say, where education is a necessary component of access, rather than integration.

DR. REEDE: Or possibly mention both the public and the health professionals, sort of public health mentions specifically the education of this body as an integral component.

MS. CARR: Tell me what to do. I was so engrossed in that.

MS. ZELLMER: Under the next whereas, instead of "such integration," say "education of health care and public health professionals, and of the public is a necessary component of access." Does that sound right?

DR. REEDE: I'm sorry. Either one.

DR. FELIX-AARON: The fourth whereas, or Brad's whereas. I think one of the points that Mr. Citrin made that wasn't reflected in this whereas is you name cost, sort of the media distortion, and the role of expanding technology that can either reduce disparities, or exacerbate disparities. I'm not sure that whereas, that third point, was captured in that whereas.

DR. REEDE: You want to offer some wording?

DR. FELIX-AARON: Exacerbate disparities, health disparities.

MS. CARR: This is a --

DR. FELIX-AARON: I'm not asking for there to be a separate whereas.

DR. REEDE: It is just another item to be mentioned.

DR. FELIX-AARON: Sort of the urgent need for this.

MR. MARGUS: It sort of belongs maybe in the next whereas, related to access to.

DR. FELIX-AARON: Where is education?

MR. MARGUS: Isn't there a place where we talk about new technologies?

DR. REEDE: No, actually, I think the issue around exacerbation of health disparities belongs up with the other urgent areas.

DR. FELIX-AARON: Yes. Sort of where we talk about the impending crashes.

DR. REEDE: Down? Where insufficient and training can lead to?

DR. FELIX-AARON: Right. So whereas insufficient education and training can lead to inaccurate disease diagnosis, and misguided management.

MS. CARR: Do you want it before costs, or after?

DR. REEDE: Before cost. Last, okay.

Muin?

DR. KHOURY: The idea captured here is evidence-based health care prevention. When we talk about access and education of public health professionals (inaudible), we're saying education is very important for the evidence-based practice of medicine. So maybe we can repackage that paragraph in a positive light or a negative light, because we're talking about sufficient education can lead to that stuff. (Inaudible.)

DR. REEDE: That was going to be my question. How would you massage this?

DR. KHOURY: I mean, just the same thing, a necessary component of access, a necessary component of evidence-based practice of medicine and health care, whatever you want to say. Really, education is a component of for various reasons, not only access.

MS. CARR: Muin, are you saying that should replace the "Whereas, insufficient education"?

DR. KHOURY: Yes, or put it somewhere in there.

DR. WINN-DEEN: Sarah, why don't you just put education and training prevent inaccurate or (inaudible) disease, so it is not a negative.

DR. KHOURY: If I could use the word "evidence-based," that's all. If we can find a place for it, that would be nice.

MS. CARR: Well, and I guess positives are always better than negatives, but I think Brad was sort of -- well, it is in response to your own concern that we need to call attention to a problem, I guess.

DR. WINN-DEEN: Well, what about if we just add the evidence-based medicine thing in the one that you were working on that ends in "of access," evidence-based medicine improved prevention and public health, and whatever buzz words we want to put in

there.

MS. MASNY: Or we could put it in the higher up with the, "Whereas advances in genomics have the potential to move us to a preventive model of health and evidence-based practice to greatly improve the health status." Because that is going to be the mechanism by which we're going to improve the health status and outcomes.

DR. HACKETT: If you're talking about evidence-based medicine, isn't that entirely a third new topic that might confuse things? We're talking about genomics, genetics, and then evidence-based medicine.

MS. MASNY: I would think that the implication there would be that now that we understand the biology of the disease, or conditions, that that is going to be the evidence base. So I think it goes hand in hand with the genetics and genomics.

DR. HACKETT: But that is such a big topic by itself, is the only concern.

DR. REEDE: I think it is written where it is the application of evidence-based medicine. I have no problem with it being printed that way. Do others want to weigh in?

MS. CARR: What about what Agnes was suggesting? Were you saying that we should modify the second whereas in some way? Or does this take care of it?

MS. MASNY: That is what I was suggesting for the second one, because I think that the issue of the preventive model that was suggested, as well as evidence-based is the actual cause, or the thing that precedes the health status and outcomes, much more so than related to access.

MS. CARR: What would you suggest, then?

MS. MASNY: Just that whereas advances in genomics have the potential to provide evidence-based practice, and greatly improve health status and outcomes.

DR. REEDE: Any other comments on the whereas' so far?

DR. WINN-DEEN: Do we want to say evidence-based practice in medicine, or something, instead of just evidence-based practice? Practice of what?

DR. TUCKSON: (Inaudible.)

DR. REEDE: Reed, we can't hear you.

DR. TUCKSON: Can you hear me?

DR. REEDE: Yes.

DR. TUCKSON: (Inaudible.) How does that read now?

DR. REEDE: How does it read now? I'll read it for you. "Whereas advances in genomics have the potential to facilitate evidence-based practice of medicine and greatly improve health status and outcomes."

DR. TUCKSON: The difficulty here is needing the word evidence-based practice. The genetics doesn't facilitate evidence-based practice. What is the evidence for the (inaudible) knowledge of whatever the discipline is. So advanced genetics (inaudible) into the guidelines and the actual practice of (inaudible).

DR. KHOURY: I agree with Reed. I agree with what Reed Tuckson just said.

DR. REEDE: Reed, would you like to make a suggestion for how we might rephrase this?

DR. TUCKSON: I think if I understand (inaudible) advances in genetics will lead to more (inaudible) understanding of disease process issues, and will (inaudible) better guidelines around what interventions genetic (inaudible) effective, and appropriate.

MS. CARR: Reed, we have modified it along the lines you suggested. So now it reads, and just make sure it is what you suggested. "Whereas advances in genomics will lead to more precise understanding of disease processes, and will provide better guidance on the application of therapeutic and preventive strategies," and I guess I lost you after that.

DR. TUCKSON: No, that's much better.

MS. CARR: Okay.

DR. LEONARD: But then can it just read, "to greatly improve health status and outcomes?" So take out, "have the potential to facilitate," right?

DR. REEDE: We have incorporated evidence-based practice in another section. Do you want to read that one again, also?

MS. CARR: Okay.

DR. McCABE: Before we leave that one, the editor in me sees a split infinitive. Can we take the "greatly" out, please?

MS. CARR: Okay. The second reference to evidence-based medicine reads, "Whereas education of health care and public health professionals and the public is a necessary component of access and the application of evidence-based medicine."

DR. McCABE: Reed, could you mute the phone in between, please? We're getting some feedback and echo.

DR. LEONARD: That's like two concepts in one whereas. I don't see what access has to do with the application of evidence-based medicine. Those are two different concepts, and they need to either be split or --

DR. REEDE: Dr. Khoury?

DR. KHOURY: Why don't you split them? Have two whereas'.

DR. REEDE: Is there agreement on this? Okay. The next whereas reads as, "Whereas, through a survey of Federal agencies on their role and activities in genetics education, training, and health workforce analysis, it was found that Federal efforts are focused on enhancing access through facilitating the translation and appropriate integration of new genetic technologies into health care and public health."

DR. KHOURY: Is that all the federal survey found was related only to enhancing access? Or everything else? It seems to me that there was more than that, and maybe I missed that in the last meeting when you guys discussed this. But it seems like the focus of the federal efforts is not only on enhancing access, but a whole bunch of other things as well.

MS. CARR: Well, I think this is probably a distillation and sort of boiling it all down. But if in doing this, we have neglected to highlight something important, we can just add it here, I think, if the committee agrees.

DR. KHOURY: Well, the whole concept of translation and appropriate integration includes access. So if you just say that the federal efforts are focused on translation and appropriate integration, because without just highlighting enhancing access, it seems to me that it is too focused. Just take away "enhanced access." That's it.

DR. McCABE: Do the other federal agencies agree with that? Anyone who disagrees?

MS. CARR: Well, the access agency isn't in the room at the moment, so we might want to come back to that.

DR. HACKETT: A quick question. Would you want to change that to genomics, or just leave it as genetics? Both the first and last sentences.

DR. REEDE: Genetics and genomics?

DR. McCABE: I would make it genetics and genomics, I think.

DR. REEDE: I would suggest that when HRSA returns, we revisit this. The next whereas is, "A solicitation of information from educational and professional organizations, identified the following needs in genetics/genomics education and training." Those needs were identified as, "Inventoried, widely relevant clinical applications stemming from advances in genomics; educational models that use such applications to clarify how genetics/genomics should be integrated into practice; a broadening of the focus of education and training from genetics to genomics; appropriately trained faculty; and training programs that address the interface of, and interaction between, genomics and public policy." Khoury?

DR. KHOURY: I would suggest to revisit family history here as under its

own bullet, or one of these bullets. But it could be its own bullet.

MS. CARR: Well, I think we'd have to make sure that the information that came back from these organizations, that is what this bullet is about. Amanda or Joan, was the family history highlighted in the survey response?

DR. REEDE: No, it wasn't mentioned there. But one of my questions would be, this is a solicitation of information. If you consider it a solicitation that included the survey and the roundtable, in that case, it could be included.

MS. CARR: And the two changes that are here are reflective of comments made by the roundtable, too. So how would you like to add it, and where?

DR. KHOURY: It could be under the third bullet, "A broadening of the focus of education and training from genetics to genomics, including."

MS. CARR: Which includes the point Peter --

DR. KHOURY: Which includes family history tools.

DR. REEDE: One of the other areas that was mentioned, I think, by Dr. Whitcomb, in addition to the clinical applications, he talked about the need to access patients, and this isn't reflected here. Do we want it to reflect that?

MS. BERRY: I don't know if it's accurate to say, but this gets to the point about how significant is the problem. Is it accurate to put in the beginning part before the bullets that these are urgent needs? Use that modifier? I don't know if everyone would agree that every one of those is urgent, but that would sort of add some oomph to the resolution, if you think that is accurate.

DR. LEONARD: Can I make a suggestion in the bullets? The family history tool is really more a part of the second bullet, which is integrating genetics and genomics into practice. The way that you're going to do that in general practice is by use of family history tools, more than a broadening of the focus of education and training from genetics to genomics.

MS. CARR: And maybe in this case, it could read "including," rather than "which includes."

DR. LEONARD: Or "through the use of." Well, yeah, you could just say "including," or "through the use of." Whatever.

DR. REEDE: One of the areas that was mentioned in the comments related to the use of the Internet technology and those types of things, and I'm wondering if there is not a way to integrate some of that, along with the information technology that we're talking about here. The importance of this is sort of the future area.

DR. LEONARD: Well, it could be through the use of family history tools, information technologies, and
web-based practice tools, or things like that. That is basically what we were talking about, as a way to get it into the hands of practicing physicians, which I think is what this second bullet is really getting at.

DR. REEDE: I think it's fine. I think the more we can link the concepts across, and since information technology came out so much today, and it was mentioned in another way, but it was mentioned in the responses, to have it incorporated here would be useful.

Agnes?

MS. MASNY: Under these bulleted items, during the roundtables, it was mentioned several times about the importance of the certification, licensure requirements, and things like that. Someone had mentioned that it should be included in the whereas as to why education should be mandated.

So since the certification question was one that we had with all the survey participants, as well as in the roundtable, if the group thinks that a separate bullet item about the importance of mandating --

DR. LEONARD: Well, I think the point was made that unless you mandate it in the certification or licensure, whatever, by those bodies, it is not going to change in the

curriculum.

DR. REEDE: I'm wondering if a way, since so much of that is occurring at the state level, or through private organizations and not really the government level, for part of the certification licensing, so the licensing is occurring at the state level, I'm wondering if there --

DR. LEONARD: But accreditation is more at a national level, so there are accreditation bodies. The licensing is more state by state.

DR. REEDE: Right. So I'm wondering, just being very specific, and not sort of putting the licensing, credentialing, and accreditation all together, because it is difficult to mandate that from a level that does not really control that area. So are you speaking specifically to the accreditation here? A bullet specific to accreditation?

DR. LEONARD: Well, I actually found it very frustrating to know that for physicians, that there is nothing that can be done nationally. That is pretty pathetic, frankly.

DR. McCABE: Well, I think what can be done nationally is to work with our boards, our professional boards, and those are the organizations that set standards nationally.

DR. LEONARD: And that's more accreditation, rather than licensure. So maybe if we want to put something in about national accreditation standards that, or the need for national accreditation standards to drive the incorporation of genetics into the curricula of educational bodies, or whatever. I don't know. I can't say that again, though.

DR. McCABE: Then make sure we put accrediting and reaccrediting, because in fact it is the reaccrediting that is required these days that is even more powerful in keeping the standards up.

DR. REEDE: The reaccrediting also addresses parts of the issues that you raised about what do you do about physicians and health providers that are already in practice.

MS. CARR: I'm sorry, but I didn't get that.

DR. LEONARD: It would be need for --

MS. CARR: I'll just say "need" at the end, but we have national -- remember, this is the urgent needs of the --

DR. LEONARD: Okay. National accreditation standards. Accreditation and reaccreditation standards, sorry.

PARTICIPANT: "Accreditation" is a facility term. I think you're meaning "certification."

DR. McCABE: That's right. It's certification, and then recertification.

MS. CARR: So are we changing this?

DR. LEONARD: Yes. "Certification and recertification." "Standards for genetic education, or genetic and genomic education to drive" -- or is it education or proficiencies? Or competencies? "Genetic and genomic competencies to drive the" -- I don't know what you want to call drive.

MS. CARR: Influence?

DR. LEONARD: "Influence the incorporation of genetics and genomics in educational curricula."

DR. REEDE: I have a question. Is this better under a whereas, or should this be one of the recommendations that should be put forth?

DR. LEONARD: Well, this is something that they identified, at least in the discussion here, at least one person said that when there are mandates to provide certain types of education, that is what drives the curriculum changes.

So we may want to sort of take that as something that we could resolve to do also, but that was something that they were saying is a need. If you're going to change the curricula for many health professionals, then it helps to have accreditation standards that include genetics.

DR. WINN-DEEN: I think the other point was that we're not looking for people to become certified in genetics. We are looking for them to have standards for genetic and

genomic competencies in order to influence the incorporation of genetics into genomics in educational criteria across disease areas, or across practice areas, sort of that concept that we're not just looking for some specialty in genetics, but that this crosses all medical disciplines.

DR. REEDE: So across disciplines?

DR. WINN-DEEN: Yes.

DR. LEONARD: Or could you say genetics and genomics in general, health care education curricula, or something?

DR. WINN-DEEN: Yes, just so that we're clear that --

DR. LEONARD: You're not creating specialists. We're creating competent generalists.

DR. WINN-DEEN: Right, or whatever, competent subspecialists.

DR. REEDE: Any other whereas? Robinsue?

DR. FROHBOESE: Yes, I have another suggestion for an addition. I think another central theme that came out of the survey of organizations, and that we've heard this morning which is also reflected in the recommendations, is the cultural diversity within, and the cultural competency of health professionals in genetics or genomics. So I would suggest adding that as a bullet.

DR. LEONARD: But that is something that genetics health professionals do. Do you hear that being stated as something that needed to be done in general for all health care providers?

DR. REEDE: I think it was felt by all. It wasn't just for the specifics of genetics, it was across the board.

MS. CARR: Would that be incorporated into the appropriately trained faculty? Or that would apply to all practitioners as well?

DR. REEDE: All practitioners.

DR. McCABE: While Sarah is working on that, let me just do a little bit of housekeeping. That is that we're running over the allotted time for this, but I think that it is quite appropriate that we do that. The coverage and reimbursement, we probably are not going to complete discussion of this afternoon, and that will continue, I'm sure, into the next meeting.

So I'm going to take the Chair's prerogative to extend this session. I just want to check, Reed, are you able to be with us for awhile?

DR. TUCKSON: (Inaudible.)

DR. McCABE: It sounds like you are commenting from outer space somewhere, Reed.

DR. TUCKSON: (Inaudible.)

DR. McCABE: Sorry. We really can't hear you.

DR. TUCKSON: Can you hear me now?

DR. McCABE: Not really. Is there any chance you can get to a land line, Reed?

DR. TUCKSON: (Inaudible.)

DR. McCABE: You sound really cool, but we can't understand a word of it. (Laughter.)

DR. TUCKSON: I'll call back on a land line.

DR. McCABE: Thank you.

DR. REEDE: Since HRSA is back in the room, there was one of the whereas' where we changed the wording and removed "enhancing access," and wanted you to weigh in on that, to read it, and give any comments.

DR. FEETHAM: I was here for that part of the discussion, and I think that clarifies and strengthens it.

DR. REEDE: Okay. Is that it for the whereas'? Can we move to the --

MS. HARRISON: I have one comment. If we can just go back to Brad's

whereas. I wanted to try to make it even a little bit stronger. We had put "training can lead to," and I was wondering if you could change it to "is leading," because we know that it is happening now from the two stories that people have said.

MR. MARGUS: It could be "has led."

MS. HARRISON: "Has led," or something like that. You know it is happening.

DR. REEDE: If we're in agreement, do you want to go through these again just briefly?

MS. HARRISON: I see you're scanning through the rest of them. I don't know if we can change other verbs in there.

DR. McCABE: We're probably going to have to have this edited. What we have done typically in the past, because it is hard to get all the grammar right while we're doing this. So Sarah, can I volunteer you and your staff to work on this this evening?

MS. CARR: Yes.

DR. McCABE: Okay. And then bring it back tomorrow. I think that will be a more efficient way to go to get as detailed as we can, but not to worry too much about the grammar, having tried to unsplit an infinitive myself.

DR. REEDE: It's more are there any other concepts that we should include within this section?

DR. McCABE: What I would suggest is that we go to the resolutions per se, and then do a quick readover at the end to see if there is anything we pick up, because the two may inform each other.

DR. REEDE: Resolutions. "As such, and in light of the importance of ensuring that the benefits of the genetics/genomics revolution are accessible to all Americans, the committee urges the Secretary to take the following steps to ensure that genetics education and training of all health professionals is adequate." I think it would be, "All health and public health professionals," that would be changed.

The first as currently written. Let me turn, because these have been changing. Actually, Sarah, it is easier for you to read than for me to try to do this.

MS. CARR: Okay. Let me read the first one. "Promote and actively incorporate into departmental policies and programs the philosophy that genetic information, which includes family history information, should not be treated as exceptional, but rather as part of the spectrum of all health information."

DR. REEDE: One of the comments that was returned with regard to this is the question of talking about exceptionalism, and this language, to the extent to which it is compatible with the language that we're using when we talked about direct-to-consumer marketing and wanted to know if there was any comments.

MS. CARR: I think what you are saying is someone pointed out the fact that what we are suggesting in the direct-to-consumer marketing resolution is not compatible with this recommendation. I think in Reed Tuckson's comments on the coverage and reimbursement report, he also took note of a couple of places where it appears to recommend a more exceptionalist approach.

I think the committee in March, when addressing the issue of genetic exceptionalism, concluded that it might be necessary to assess the need for exceptionalism, or the problems associated with it on a case by case basis. So I think you have left yourselves room to be inconsistent, I guess.

DR. WINN-DEEN: I think in this case, what we're talking about is really sort of not so much that genetics is exceptional but that it happens to be the new thing that we have to integrate into medical practice today, and so it is just the latest thing which we need to deal with.

DR. LEONARD: I think also you're talking about genetics as a subspecialty, and moving it from subspecialty practice to influencing every health care and public health

professional. So I think it is more that it is not a subspecialty, so we may not even want to use the word "exceptionalism," and talk about it as specialized as opposed to general practice. Genetics is going to influence all of medical practice, so it has got to be part of every health care professional's training.

DR. WINN-DEEN: So this should not be treated as exceptional, it should not be treated as a subspecialty, or as a specialty.

MS. CARR: Or what if you just said, "should be treated as part of the spectrum of all health information?"

DR. WINN-DEEN: Yes, that's fine. Just take the "not" and the "exceptional" out.

DR. LEONARD: Sarah, in the preamble paragraph, in the last sentence, can you change "all health professionals," to "all health care and public health professionals?"

DR. REEDE: Reed, are you back again?

(No response.)

MS. CARR: And the second one isn't really integrated yet completely, but this part was part of the prior one. "Promote the integration of genomics into the education and training of all health professionals," and this is a fragment, I think, from the first one, "so it should be treated and viewed." Actually, I think it belongs up there.

So the second one is, "promote the integration of genomics into the education and training of all health professionals." Here is where we wanted to build in the suggestion that the Secretary incorporate in the health information technology initiative, some reference to family history, or incorporate some electronic family history tools into that initiative.

DR. McCABE: Sarah, I would suggest that we separate out "add" into another resolution. It seems like we're mixing education and the Secretary's initiative, plus it will make it more obvious to the Secretary if it is not buried as a second part of the second resolution.

DR. REEDE: Wherever we have "health professionals," if we could sort of in the wordsmithing later, change it to "health care" and "public health professionals."

DR. McCABE: Reed, are you back with us yet?

(No response.)

DR. HANS: Just on this one, I guess I have some concerns about, because the discussion about CAHIT was broader than what actually the topic of this resolution was of education and training for health professionals. It is a much broader topic than just that.

So I would suggest one of two things. One, to narrow this down to just talk about the educational components to be considered in CAHIT for genetics information. And then put the question to the committee, if you want to take up the broader issues of CAHIT in the interface of this committee, sort of as a separate something, whether it is a letter, or some other separate topic.

I'd just be concerned if you'd try and capture everything in this resolution, because it is a more narrow topic than this opportunity offers. So this, if you want to narrow it down, could say something, "incorporate family history, tools, and practitioner educational tools, support." Instead of "tools," use "support," Sarah. And then I'm not quite sure where we're going with privacy and confidentiality, but there are a whole bunch of issues that may not fit with education and training.

DR. LEONARD: Can I suggest that practitioner educational support, really what you're looking at is point of care educational support? Because practitioner may be misconstrued as CME, or continuing education, which you really want it at the point at which you're seeing the patient.

DR. REEDE: I think I would also change the order. So I'd have as what you have as Number 2, I'd move down.

MS. CARR: So it would be Number 4?

DR. REEDE: Well, it would become 3, and 3 would become 2. While you're

doing that, I'm going to read the next recommendation. "Engage other health professionals, private sector, colleagues at the Federal and State level to facilitate the cataloging and dissemination of genomics applications to clinical medicine and public health, and models based upon these applications to ensure genomics has impact now, as opposed to far off in the future." Any comments on this?

DR. LEONARD: There was a suggestion during this discussion to recognize the efforts of NCHPEG in this point, and I don't know how we do that.

DR. WINN-DEEN: Well, we could just say engage health professionals, such as NCHPEG. Use it as an example.

MS. MASNY: But I think here, it is even stronger than just to engage them. I think some of the resources we heard about, both through HRSA and through NCHPEG, that what we want to make sure is that these resources are utilized, and that the public, and even the professional organizations and academic institutions know about them, so they don't have to reinvent the wheel. So somehow if we could make it stronger in terms of utilizing existing resources that have been developed by state and federal organizations.

DR. REEDE: Giving NCHPEG as an example?

MS. MASNY: Yes. We could give NCHPEG and HRSA as an example.

DR. McCABE: I would just argue private, state, and federal organizations.

DR. REEDE: And not use an example?

DR. McCABE: It's fine to use an example, I just think we need to recognize the private sector.

DR. REEDE: Kay?

DR. FELIX-AARON: In reading this point, I agree with it in principle and what it says, but I was just struggling with sort of what the federal rule is here in terms of if we have an audience, and I imagine this is directed to the Secretary, how do we want to use that space that we have with the Secretary?

So I would think like for matters of just being effective as a document, as well as being efficient, I think this needs to be done, but sort of what the Secretary's role here is, isn't readily apparent to me. So I'd just like somebody around the committee to just clarify for me what the Secretary's role is here.

DR. WINN-DEEN: Well, it seems like it is sort of covered in the next point after this one, where we talk about specifically federal.

DR. FELIX-AARON: Right. I mean, that is one of the rules that the federal government has provided technical assistance, and I think the federal role is to do things that cannot be ordinarily done in the private sector because there is not the will, or there is not adequate incentive to do it. It is not clear to me that that recommendation captures the unique federal role.

DR. WINN-DEEN: So maybe what we want to say is partner with the private sector and state organizations, and encourage --

DR. FELIX-AARON: I think the one below says to support efforts. The point below, provide adequate program and technical support, but it is not clear to me why the federal government should be engaged in inventory and the cataloging process.

DR. LEONARD: Well, actually, the CDC is doing that, aren't you, Muin? You're cataloging the most common genes, and the most common diseases, and so in a sense, you are providing some of that information that would take genetics and genomics to the family practitioner.

DR. KHOURY: I think what I'm hearing Kay say here is that you need to give the Secretary sort of the best possible chance for integrating genomics, genetics, and family history into whatever Department-wide initiatives are going on. I think under Number 2, the Secretary's Health Information Technology Initiative is something that he can take and say okay, I'm going to integrate family history tools into that. But there are a number of other initiatives

that the Department has. For example, the STEPS initiative, which is a big initiative for the prevention of common chronic diseases, and health promotion. That is really prevention oriented.

So by encouraging the Secretary to look across the board and say okay, these are the initiatives that I own, that I've started, but so far I haven't seen the role of genetics and family history in it. But now, there are more legs I could stand on and use these as forums to empower big initiatives that use and integrate genetics, rather than be a standalone activity for the Department.

And so I think singling out the Health Information Technology Initiative is one thing, but I don't think we should focus on just one activity from coming out from HHS, we should give them a broad range, a number of activities that could touch the lives of all the agencies by using the concept of integrating family history tools and genetics into whatever we do, because that will affect the practice of health care, disease prevention, and health promotion.

That would include that last point, which is what Debra was talking about, which was what was the point about the cataloging function? It is only a minor tool, or a minor service that the Department can provide, but I think you should give the Department the broadest possible advice that affects most of the agencies, rather than one or two. That would be my advice.

DR. FELIX-AARON: I mean, I agree with that, but I also think that the point that I was trying to make in terms of to me, this seems like a small, narrow, small, function, and not necessarily something that the Secretary in his unique role would necessarily engage in. So CDC is doing it out of the programs, and I understand that.

But I agree with you in terms of providing vehicles. So to the extent possible, to provide vehicles where those types of recommendations can be tapped on, I think is extremely important.

DR. REEDE: Can I ask a question there? So is there a role sort of somewhere in between these, as we look at these multiple federal efforts? And having some place or some mechanism for understanding what is being learned within those efforts, and to link that back to the private sector, and to the educational sectors? So that as this work is being done, it doesn't end up being done in isolation, but the federal government is actually cataloging the work that it is doing in a way that it can be disseminated easily across these groups. Slightly different, but I think if you're not sitting in this room, you may not know about the work that is being done across the multiple agencies.

DR. FELIX-AARON: I mean, one of the things that come out of this Department and the Secretary is the issue of coordination, and coordination around the departments, and speaking with one voice. So I think, if what we have here could be framed in terms of speaking with one voice, or one Department and really understanding to make our Department more efficient and effective in that area, that resonates, at least in my mind, with what I hear coming out of the Department.

DR. McCABE: Well, if it read, "To coordinate and disseminate genomics information," would that be better?

DR. FELIX-AARON: I think so. I mean, I don't know what other people around the table think, but I would that at least at a minimum, it would. It sort of captures some of the conversations that have been going on here, and it resonates with what I hear coming out of the Department, and at least the goals of the Department.

DR. TURNER: I was just sort of agreeing that to determine what the Secretary's role is is important, so that we can phrase these in ways that he is able to respond. In addition to what she is saying, I'm struggling with the softness of the language. Someone earlier suggested that we stand up a little taller and say, we may not want to go as far as direct, the integration of genomics into the education, because I don't think he can direct things.

But to look at where we are, and then sort of envision how would he carry this out, I think the words she just mentioned are the operative words, if you will, that would get the

job done. So I would suggest that we think in terms of, do we want him to make a phone call? Or do we want him to take this to some meeting? Or how do we want this to play out?

DR. REEDE: So coordination, dissemination, and pulling it together.

Debra?

DR. LEONARD: From this discussion, can we kind of take Number 2 up there, and I think what I'm hearing is that we pulled out one initiative, but there are steps, and there are other things, other initiatives. So maybe we should say incorporate genetics, family history tools, point of care, and educational support in the initiatives of the Department of Health and Human Services. For example, CAHIT, STEPS, that type of thing, and coordinate the dissemination of this into practice through private, state, and federal efforts.

But get in there that you want these things developed through the Department of Health and Human Services, and then you want that information that's developed there disseminated into practice. That is going to involve coordination and use of this information by professional organizations.

DR. REEDE: All right. I hear what you're saying. One of my questions for the agencies is the extent to which they can coordinate how the professional societies actually use this, as opposed to a coordination of how they disseminate the information that they have gathered. So I sort of see sort of a collecting what is going on, and being able to disseminate that, and to work with other organizations, but not really being able to coordinate after that, the activities of those professional organizations.

DR. FEETHAM: I think moving the discussion that we're having now about showing and giving the Secretary the guidance to look at this within all those key initiatives is really critical, and is a broader scope than adding it into some of these more specific processes. You're closer to that in Number 1, and promote and actively incorporate, and I think if you bring this overall concept of how this fits within many, or probably all of the Secretary's initiatives, I see as higher up the list, and more of an overriding. From then on, you're showing him some examples.

But I think you are losing it if you try to add all of those things, such as, such as, but I would bring it up, and I think it is closer to your current number one of incorporating interdepartment policies, but you're really talking about Department initiatives.

DR. REEDE: Ed?

DR. McCABE: I would ask that we try and get the big points down over the next 10 minutes, and then wrap this up. We're going to then take like a three to five minute break to try and make sure that we can get back to Reed and have him hear us, as well as us hearing him, and then proceed on. But if we can get the big ideas, we'll try and rough them out this evening.

DR. REEDE: Okay.

DR. LEONARD: Another big idea that needed to be added as a separate bullet point was the education of the public. So that's a whole separate point that needs to be added.

DR. HANS: I'll wait for Sarah to get back down. Where I thought you were going, there are sort of two directions. One is to encourage, promote, and raise with the Secretary and the departmental leaders to incorporate the sort of concepts of genomics and genetics into a variety of ongoing activities.

The other direction which I thought you were going there for awhile, and now I have lost track of the numbers there, but is to say something like recasting one of the numbers that is up there, direct the HHS agencies to work together, and with federal, state, and private partners to, and I don't remember what words we used, collect all of the genomics education programs, and I don't remember where we were. And then work again with these same partners to promote the use of those materials through the various avenues that they have.

If you wanted to encourage HHS to go farther, even then just within HHS

agencies, you could even ask that it be done in an interagency setting, like through the Quality Interagency Task Force that exists, that is a forum for interagency cooperation.

The second step is once you have sort of the collection in place, and you have sort of made the federal statement that this is what we should be doing, you then ask all the agencies to go back and look within their own programs, within their own regs, within their own activities, how do you appropriately incorporate it into what they're doing? Which certainly for VA and DOD, for instance, who run health programs, you have a more direct impact than you do just putting out recommendations to health professionals. So I'm sorry, Sarah, you probably weren't able to capture all of that.

MS. CARR: Sum that up.

DR. HANS: I was really looking down there where you have the red Number 1. So instead of framing it, because I thought that is where the discussion really was, instead of framing it as engage other health professionals, but rather to say direct HHS agencies, or direct the HHS to work among themselves, and with the state, federal, and private organizations that you have listed further down, to not facilitate, but actually catalog and disseminate genomics applications, and then work together to implement, where appropriate, within ongoing activities, or ongoing programs. We can work on wordsmithing that, but I don't know if you want to go that far, to be that direct.

DR. LEONARD: My concern is that I think we're losing the spirit of what is now the red Number 1. What the educational groups were asking for were cases that are relevant to everyday practice, so that they could do
case-based education. This has now morphed into something that is not getting at, because it wasn't clearly stated, I think, in this one to begin with, that what you were looking for were cases that you could use for educational purposes, for case-based teaching.

So now that whole case-based teaching, the need to get the cases that are out there in everyday practice today, has been lost from this list.

DR. REEDE: I'm wondering if that is not a separate issue in terms of support for programs that will develop and help disseminate these specific cases, or interactive learning modules, or whatever that might be.

DR. LEONARD: Right, but it is now not in this list anymore.

DR. REEDE: I'm wondering if that shouldn't just be listed as separate. This list is going off in another direction, so I'm wondering if this is a separate entity.

Two other things, and given our 10-minute time frame that is just about used up, if we look at some of the other recommendations, there was one with regard to what was Number 5, "encourage accrediting, licensure, and certification of health professionals," that that be changed. That was one of Debra's recommendations.

DR. LEONARD: It would be of health care and public health professionals.

DR. REEDE: Professionals.

DR. LEONARD: So certification bodies for health care. So up in the first line, Sarah, bodies for health care and public health professionals.

DR. REEDE: With regard to what was Number 6, a specific mention was made for us to keep in mind that cultural diversity and competency include the disability community. So I would question whether or not you'd like to add specific wording with reference to the disability community for Number 6.

Another item that we actually don't have time to word smith right now, but it was a strong point, was to have a recommendation that related to the ethical, legal, and social issues in training.

DR. McCABE: Any other big issues?

MS. HARRISON: I just had one about Debra's point about the public. I see that Sarah is trying to word smith something there to represent the thought. I just wanted to point out that Joe McInerney in his public comments did provide some wording for that, which I

thought was pretty strong. So maybe that should at least be considered. One thing I wanted to add to it was to say that the initiatives should be done in a culturally sensitive and appropriate manner, so that we know that the initiatives that are put out there, that it is encouraged that some of them can be focused on certain communities that may otherwise not respond to other types of education.

DR. REEDE: Thank you.

DR. McCABE: Any other big issues?

(No response.)

DR. McCABE: If not, Sarah, we can try and work on these tonight and bring them back. But I think we do want to move on, so that we don't shortchange the public. What we're going to do now is take a three to five-minute break. Please don't go far. We are really just trying to link back up with Reed Tuckson. So please try not to go far.

(Recess.)