

**Closing Remarks**  
*Reed V. Tuckson, M.D.*

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DR. TUCKSON: All right. We are just going to have a couple of minutes, and then we know that some of you really need to get out of here, so we're going to end a little early, I think.

Let me summarize a couple of things I think that we said that we would do. This is not going to come out real well, because I thought I was going to have a few more minutes to actually sort of organize this.

Anyway, the main thing is that Sarah knows what we're supposed to do. On the genetic discrimination discussion, before you go, Muin, because there is something that says you were supposed to do something. On the genetic discrimination, we are going to do the DVD. I did that narration this morning. So we have approved the script, and that is moving forward.

The public comments to the Secretary are being collected, and those will go forward to the Secretary. The legal analysis, we are not going to wait for the legal analysis to get done. But in the body of the letter to the Secretary, we are going to urge the Secretary to use all of his influence to expedite the legal analysis from the various departments and everyone that is involved with that. Then we are requesting that the Secretary hold the stakeholder meeting to help broker any differences that may exist in that community to move that forward. So those are the things that we agreed to on the genetic discrimination.

On the health informatics infrastructure, I think we wanted to send a letter to Brailer saying thank you, and urging again that we want them to remember what we are trying to do here, the family history issues in genetics being important as he unveiled his strategic plan. Muin is to work with Alan Guttmacher and/or Frances to draft the letter in fact to Brailer.

That's what you're doing. You already did it.

DR. KHOURY: No, actually, we talked with Alan yesterday. So I think Alan is taking the lead on behalf of all of us, and we'll contribute.

DR. LESHAN: We'll work with you.

DR. TUCKSON: Oh, it's the old wait for Alan to leave, and then give him the assignment. That will teach you all to leave.

For whatever the Rodney Howell committee, what is it called?

MS. CARR: Heritable Disorders.

DR. TUCKSON: Heritable Disorders. Any of you that have comments that you want reflected there, go to Joe so that Joe Telfair can carry the water for us on that committee.

On the reimbursement, I'm not going to summarize that again. If you all didn't get that the last time, shame on you. So I want to also just -- large pop?

MS. CARR: Yes. On large population studies, we are writing a letter to the Secretary with a number of points that we're going to make.

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DR. TUCKSON: All right. So we've got the large pop. That's exactly right. So we've got that. That's in our notes.

I want to welcome again to the committee Joe Telfair. I thought Joe was terrific. What a terrific addition to the committee.

Kevin, we'll just wait for him to leave, and then we'll say nice things about him.

(Laughter.)

DR. TUCKSON: But Kevin, really welcome.

I just think this is really fun. What a good group.

I think all of you would join me, by the way, and the ex officios, thank you all very much for coming, and all the contributions that the ex officios made. It is terrific.

The webcast people, thank you all for that. Again, there are a lot of people out there that care about this. So thank you for that.

Thanks to the soundman. You were terrific keeping us on track.

Sarah and the team, always just stellar behind the scenes. Every single person is to be commended.

(Applause.)

DR. TUCKSON: Now, the people that deserve the biggest applause are the audience. I mean, how they can sit through this stuff?

(Applause.)

DR. TUCKSON: And they don't get to talk and just have to be talked at. But we really appreciate your involvement and expertise.

Does any member of the committee have any last words?

MS. HARRISON: I have one last comment. I think I always say this at the end of the meeting. I still want to at least keep in our minds that we do have a duty to the public to let them know about our proceedings and things that are going on, and that the Federal Register may not be the best place. So I think we still have a duty.

DR. TUCKSON: Which I'll piggyback on also. Again, that comment that I made at the beginning of the meeting, I still want us to somehow, even though we've got a lot on our plate, how do we get at this education of the American public? Not just even about, although it is important what you are saying, it stands on its own about what we are doing, but it is educating the public around these issues.

I think that's important. I'm glad we got it into the recommendation at the end for the Secretary on the coverage and reimbursement issue, where we can start to get the Secretary using the

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information distribution mechanisms at his disposal to try to educate people about these things. I think that's important, so I'm just piggybacking on that.  
Does anybody else have a comment?

(No response.)

DR. TUCKSON: Well, with that, it was a hard two days. Good for you all. Thanks a lot.

(Whereupon, at 3:47 p.m., the meeting was adjourned.)