

Review of Draft Progress Report
Steven Teutsch, M.D., M.P.H. and Paul Wise, M.D., M.P.H.

DR. TEUTSCH: Welcome back to our final session for this SACGHS meeting. Thanks to all of you for returning. I know people will start drifting out.

I first want to express my thanks, of course, to Sarah and her incredible staff, who, meeting after meeting, somehow make those of us who sit up here look good. It is incredibly appreciated. They do a terrific job behind the scenes, and it is much appreciated.

Thanks to Abbe and her folks, who help us out with so many of the logistics.

We have just a couple things that we want to wrap up here before we conclude the meeting. What we wanted to do is bring to closure the discussion we had this morning. What you have up here is the framework that Paul had suggested to us as we take this forward to the new administration. This is partly so you can see the actual words that we intend to use, first related to our energies that will be devoted to improving the healthcare system and how genetics fits in with that.

The second is on genetics and public health and population-based prevention. I have to do a mea culpa here because I gave that rather short shrift in my summary. My public health roots have come back to haunt me. I can't go to L.A. County and join the health department if I don't flesh this out a little bit.

I breezed through some of the agenda. I will work with Katy Kolor and with Joseph to try and identify the one or two items that we can move forward with that are pretty specific that we can have as part of those discussions.

DR. EVANS: That is the hard part because it is a very broad topic. It is hard to focus on.

DR. TEUTSCH: It is. But I'm afraid if we say something like "Assess the systems," even I will fall asleep.

DR. EVANS: I would advocate focusing on something along the lines of using genomic data to stratify populations for risk in the context of screening, something like that.

DR. TEUTSCH: Right. This actually embraces two things. We have the clinical part of the public health in the first bullet. The second part is really the population-level stuff. Yes, it could include some of the screening, but it probably needs to deal with some of the environment-gene interactions and the risks that accrue to communities, subpopulations, and things like that.

So I will work with folks to do that. Obviously, it is not going to be cast in concrete, but I think that was the distinction we were trying to make. Those of us in public health think that the clinical system is part of that rather than separate, but that is a whole different set of ego problems.

The third one is, we talked about the individual engagement that deals with, certainly, the privacy and protections issues, as well as the direct-to-consumer genetic testing.

Finally, there is that major cross-cutting issue that we all feel passionate about but it is hard to get your hands around it. It is a discrete kind of thing about the equity issues in this whole area.

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Jim?

DR. EVANS: Equity issues?

DR. TEUTSCH: It is disparities, right? Fairness, disparities. Do you prefer "disparities" to "equity"?

DR. EVANS: I don't know. It just caught me by surprise.

MS. ASPINALL: I like "equity."

DR. EVANS: "Equity" is fine.

MS. ASPINALL: "Equity" also includes access as well.

DR. TEUTSCH: Yes. Across multiple dimensions.

MS. ASPINALL: Yes, that is why I'm saying I like "equity." "Disparities," to me, has a different implication. "Equity" is broader.

DR. TEUTSCH: "Equity" is, I think, where we want to go, as opposed to where we are. Is that okay? That was your word; so that is okay with you, right?

DR. WISE: There are people who have built their careers on the difference between disparities, equity, inequality, and injustice.

DR. TEUTSCH: What I would like to do is just bring this to closure. Are there any other issues generally with this framing and what we discussed this morning?

[No response.]

DR. TEUTSCH: Hearing that postprandial slump, we will move to the last major thing. In July we talked about the fact that we would like to engage the new administration in a timely fashion. What you have in Tab 6, and I think also in your folder, is a draft letter, which I assume you have all studied assiduously, to the presumed Secretary, Tom Daschle. We have a little bit to incorporate, which is largely this, that we will incorporate into this letter.

Aside from a general framing of where we have been, some of the priorities that we think we should take up that are based on our prior reports that relate to some things that we thought were ready for quick action that he can build on the activities of the current administration, we want to talk about the future directions where we want to engage. That is basically the framing in the cover letter.

Then, in the I don't know what we call it. The attachment, the appendix, which says The Integration of Genetic Technologies Into Health Care and Public Health: A Progress Report and Future Directions for SACGHS, begins to flesh out the issues that we just identified in the cover letter.

Many of you have had a chance to look through this. I would welcome any comments.

Paul has played a critical role in drafting all of this. Paul, anything you would like to add to that?

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DR. WISE: I think our approach to this was that the cover letter was going to make the broad, general case for both the existence of this Committee and where we think the central issues are going. We have more background and more elaborate discussions, still relatively brief, in the appended document.

We didn't want this to be a laundry list of everything that the Committee has done. We didn't want it to be a laundry list of all of the things we are considering doing but rather a framing letter that would be accompanied by the more in-depth document that would be perhaps the basis for beginning the conversation between the Committee leadership and the new administration, to begin that co-navigation process that we discussed.

DR. FROHBOESE: I think the letter is very well drafted, will be very helpful to the new Secretary, and will be instrumental in making sure that this Committee's views are before the Secretary at the earliest possible moment.

Now that we have this framing of the strategic contributions, it may be good to incorporate those concepts in this letter.

DR. WISE: That was the intention. It will probably be bullets in that paragraph that covers it very broadly. But I didn't want to presume to insert these kinds of reclusterings or condensations until the Committee had an opportunity to really discuss all the clusters and how people saw it put together. So if people are happy with this, we would then put this in basically as our principles of moving forward, or what we view as our strategic contributions to the efforts of the new administration in this arena. I think our idea was to take this and incorporate it into the cover letter.

DR. TEUTSCH: While you have the floor, Robinsue, we always benefit from your wisdom on how best to facilitate these things. You have seen a transition or two. Any other things that you would suggest that we do so that we can best engage the new administration on these issues? I'm putting you on the spot, of course.

DR. FROHBOESE: No, I'm happy to contribute my views. Right now the Department is going through a transition planning process. So there is an opportunity for each operating division and staff division to meet with members of President-Elect Obama's transition team. We are actively going through this interview process right now and providing material.

I think certainly all of the ex officio members, in going through these interviews with the presidential-elect transition team certainly can bring forward their involvement with this Committee and the visions that we are setting forth now.

I think once the new Secretary is in place, then working through the Office of the Secretary and getting this letter directly to him identifying who the point person is going to be in the Secretary's office to handle these issues and establishing that contact will be the best way to get the information across.

DR. TEUTSCH: Thank you. Thoughts on the letter? Did we catch them at a weak moment or something, Paul?

DR. WISE: We just did a good job on the letter.

DR. TEUTSCH: We could have done this before lunch. I'm sorry, Sylvia.

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MS. AU: Can we just highlight the opportunities for immediate action, Nos. 1, 2, 3, and 4. Can we make them bold or something?

MS. ASPINALL: I'm sorry. Where is that?

MS. AU: On page 6.

DR. TEUTSCH: Oh, you are talking about the attachment.

MS. AU: It just blends into the letter.

DR. TEUTSCH: Sure. I agree. Those are things we do want to highlight. We debated about how to actually format that even in the cover letter. They are there as well, but it is hard to highlight everything in a cover letter. Yes?

MS. ASPINALL: I love Sylvia's suggestion. Maybe the opportunities for immediate action should go in the cover letter, not in the attachment.

DR. TEUTSCH: They are there, right?

DR. WISE: No, it is not.

DR. TEUTSCH: Which version am I looking at?

DR. WISE: I'm the one probably responsible for yanking them out of the cover letter.

MS. ASPINALL: So it is you we should blame.

DR. TEUTSCH: They are there. They just are not formatted this way.

DR. WISE: I'm the one to blame. The reason was because we are making, in the cover letter, an existential case. We are talking about healthcare reform and we are talking about broad issues of public policy. Then in the next few sentences we are talking about specific, immediate action steps, which is just nowhere going to be on anybody's radar screen until the assistants to the assistants to the assistant secretaries are in place.

My concern was just the mismatch of scale. It was jarring. It really had that cut-and-paste kind of feel. So my suggestion, to respond to Sylvia's suggestion, would be to elevate the immediate action steps within the attached document, make them bold, move it up in the document, but not to put it in the cover letter because of the mismatch of the scale of the immediate action steps with the main purpose of what we would like to get across.

MS. AU: I think that makes sense. Somehow online it looks a little bit different. There is so much information here it is hard for anybody to get through easily, but it is well written. I like the paragraphs. Maybe the opportunities for immediate action become a separate attachment that is independent and then you have the summaries there.

I understand about not putting it in the cover letter as you have now described it, but maybe having two attachments there so it is actually separable and looks different from the rest of it. Even at the beginning or end of what is a pretty substantive, six-page document, it may get lost.

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DR. TEUTSCH: That is a good thought. Yes, Charles.

DR. KECKLER: I think that is a good decision. Following up on Robinsue's point, one thing that you might want to consider during the transition is, I think it is very important to figure out as soon as that person is in place or as soon as possible who the point person will be that is coming in as part of the political administration, either the counselor for science or whatever structure is going to be put in place.

You may want to consider sending the document, the cover letter and/or the attached progress report, to that person along with the Secretary and to send it at the time when that person is there. I'm sure the confirmation won't actually take that long for the Secretary, but that person may actually become identified before the Secretary is confirmed. It may not be a political and Senate-confirmed appointee.

So you may want to time it and get that document to that person along with the Secretary as the target addressee.

DR. TEUTSCH: That is a great point. We have had an extraordinarily constructive relationship with Rick Campanelli and with Greg Downing and all the folks in the current administration. We really look forward to fostering that with the new administration.

Other thoughts, folks? Anything you would like to talk about for two hours? Is there anything else? Sarah, anything else?

MS. CARR: You got your core goals done.