

Cluster 7: Genetics and the Future of the Health Care System  
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DR.WISE: We will move on to Cluster No. 7. Mara.

MS. ASPINALL: Thank you, Paul. As Cluster No. 7, I can say it is not about money, value, education, power, empowerment, or responsibility; it is about all of those. It is not even about today but really about the future. Cluster No. 7 is not looking at any one issue but looking very broadly across the healthcare spectrum to say how do we get prepared for the future that we all talk about. What came up yesterday is, today is useful but how do we ensure the infrastructure for the future.

In Cluster No. 7 there is a focus of two key questions. Personalized health care: is it achievable; what are the costs and what are the benefits. Secondly, what are the infrastructure changes needed to foster or even adopt personalized medicine or personalized health care in the broader perspective. Those are the key pieces.

When we look at the background, I'm not telling anyone anything new here, but the current system is not working. It has high cost and poor outcomes. That doesn't mean there aren't parts of it that are working well, but as we have heard many times, the current trend and system is unsustainable and we need to move beyond that. As we found out in many areas, both health care and more broadly -- the nursing shortage is a great example -- we need to be prepared for how the future will change.

Let's look at those two key focus areas. The first one is value, cost, and achievability. The assumptions that we made here are that genomic medicine has the ability to benefit public health and that new technologies will come along, some of which will decrease cost but some of which are going to increase cost, depending on how widely or narrowly you think about the cost.

But this is still a technology and a science that, whether you call it in its infancy or adolescence, is not as robust as it will be into the future. So, considerable research will continue to be needed.

Lastly, and really the core of personalized health care, is that the greater understanding of the epigenetics, the genetics of subpopulations, is critical to benefit all people and that we need to understand how to target those interventions, whether they be diagnostics, drugs, devices, or other interventions. That is the key.

The second piece is, what is the infrastructure that we need. This overlaps with several of the other clusters. First, in healthcare delivery, how do we ensure that we have cost effective delivery and what we believe is a likely need for increased genetic counseling. In this cluster, we define genetic counseling quite broadly.

Secondly, we talked about workforce. We are likely to need additional clinical lab workforce, even if they are doing different jobs than they are doing today.

Thirdly, health information technology. Current HHS Secretary Leavitt has made a big deal about the critical piece of integrating health IT into the delivery of care and into personalized medicine.

Fourth, systems to monitor that so we don't roll out new systems of genomic medicine and not have the ability to say is it effective or not.

Lastly, should the government play a role in incentivizing business pursuits -- and we mean by that the broadest definition of the industry, not just for-profit but not-for-profit -- in the pursuit of diagnostics and genetic therapies.

We have a number of policy questions that come out of this piece. Again, the objective here is to really look forward and say how should the government -- by that, individual agencies through HHS -- help invest resources in genomic medicine.

No. 2, should the government be part of adopting a new healthcare delivery. You will see in a minute there are a number of different models that have come out. Should the government promote them. Should they get involved. If we anticipate that the medical home model might be the one, what is the infrastructure that needs to be set up to ensure that we can handle the onslaught that is likely to occur.

No. 3, financial incentives in the workforce. Are we facing a crisis that many would say today that we do not have enough people in the healthcare workforce to be able to offer these kinds of tests and this kind of science going forward.

No. 4, health information technology. What else can HHS do to promote this. Specifically, we talked about development of electronic health records and the digital storage of health data. Again, assumed many of the clusters is we are gathering much more information than we have ever had. How do we ensure that we can access that information in the future.

No. 5, quality. It is the core of the system and the core to what has been described in terms of confidence in the system. How can we ensure that indeed the quality is there and that we are able to monitor this for public health benefits. Are there surveillance systems in addition to what we have discussed before that need to be put in where we need to put the ground work in today.

Then, finally, the issue of incentives for genetic diagnostics and targeted therapeutics. This is not just about diagnostics, this is about genomic medicine in its broadest piece.

Lastly, how can the government think about these differences in population that ensure that we are focused not just on subsets that exist today but important variations amongst the populations in the future.

So, the short-term action steps. First, we talked about getting together the chief medical officers from the health plans. That is public and private health plans. They have been a group which we would say has been somewhat underrepresented in our discussions and they are a critical piece to ensuring that the infrastructure going forward is covered. We wanted to put them together, both public and private, to get their view of the future and ensure they are part of the team.

What we then looked at, and not on the slide, is working with the other HHS agencies. Many of the agencies have begun to look at what they believe is the future of health care, and we want to ensure that we are not recreating work that has already been done in other agencies.

In the last few slides, we look at brief reports. I won't go through each of these individually. They basically mirror the policy questions that say how do we look at this.

The reason we talk about brief reports, quite frankly, for a big piece of this is that it is possible for this to go on into the future such that we won't be looking into the future. We think it was critical

to ensure and put a stake in the ground on a couple of key issues, particularly around tools and incentives and the health information technology.

Lastly, there were two areas that we did believe may warrant some in-depth work. In the area of health care delivery, one example is the medical home model, the customized care centers, and genetic counseling to work with some of the other clusters to ensure that we understand what the infrastructure will need to do that going forward.

Lastly, the genetic and epigenetic variations, in which, again, working with other agencies is critical in the true delivery of personalized health care. What we wanted to ensure is, if there was data that was needed for populations that are today not represented, that we begin getting that data today and acknowledging what the gaps are so that when we have the ability to go forward that there are not groups that are left out.

Thank you.

DR. WISE: Questions.

DR. EVANS: I just have one question. It seems to me that on two of the slides, Nos. 64 and 67, there is a fairly exclusive focus on encouraging students to pursue clinical laboratory careers, which confuses me. I think if we are talking about the healthcare system that perhaps an emphasis on both laboratorians and clinicians who focus on genomic aspects of health care. I wouldn't want to confine it to laboratorians.

MS. ASPINALL: I think that is a great addition and we should broaden it. Because of the attention on the crisis literally today there was a focus on that, but I think as we look forward we need to look more broadly. Thank you.

DR. WISE: Yes, please.

MS. DREYFUSS: This is the mirror image of the questions you were asking yesterday. In several different places you talk about incentives to find diagnostics and therapeutics. I would rather have that say "promote the development of diagnostics and therapeutics" because in fact sometimes I think we see that these incentives get in the way of actually promoting them. So it is not just creating new rights, necessarily. It might be creating the right to use research that somebody else has a right on.

MS. ASPINALL: I think that makes a lot of sense. That was the spirit in which we were intending to do it. We will ensure that it is changed that way.

DR. WISE: Steve.

DR. TEUTSCH: Just one addition to the EHR story, which was mostly about data storage and records. It is really, I think, given the information that is likely to come out and the need to manage it intelligently and the difficulty of keeping it in everybody's heads, the clinical decision support part of that translates all this information into something that is useful, interpretable, and actionable.

MS. ASPINALL: Yes, so it is more specific. I think that makes sense. The report that we got yesterday on personalized health care actually has some wording that might be useful to incorporate into that. So we will change that as well.

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DR. WISE: Marc.

DR. WILLIAMS: Just to add on to that, I think that an overarching theme for all of the different clusters is the idea that almost all of them will need robust information technology in a variety of different forms to actually make it happen. I think that is implicit in all the presentations, but we probably need to be more explicit about that and also be very intentional about looking to partner with the other groups that are working on this.

In particular, as the new public-private partnership that is going to be the second iteration of the American Health Information Community gets up and running, we really need to make sure that the engagement we have had with that group to this point continues.

DR. WISE: Other comments or questions specifically on No. 7?

[No response.]

DR. WISE: Thanks, Mara.