

Cluster 6: Public Health Applications of Genomics Research  
Joseph Telfair, Dr.P.H., M.P.H., M.S.W.

---

DR. WISE: We will move on to the next cluster. Joseph.

DR. TELFAIR: Thank you very much. We in public health are very solution-oriented. To us, it is about the work and getting the work done.

I will cut to the chase. First of all, I would like to say it is really an honor to present this information. I do want to thank Dr. Fomous and particularly Dr. Kolor, who is sitting at the end of the table here, who worked with her group at CDC to help us to formulate this.

Public health, as many of you know, is a broad and diverse table. We try to look at the world ecologically to fit between the physical and the social environment in many ways, to the benefit of the general population.

We want to clarify some of our terms. Public health genomics is a multidisciplinary field that really is concerned about effectiveness and responsible translation of genomic-based knowledge and technology, with a focus on population health.

We focus on policy and actions that are needed to promote health and to prevent and control disease. We also focus on the interplay of genes, the environment, both physical and social, and behaviors. We want to ensure that the benefits of genetics and genomics are realized across many diverse populations and groups. We do this through our main public health priorities, which are assessment, policy development, and assurance. We do this from a knowledge base, an evidence base. Research forms the core.

Like the previous work before us, there is some overlap. We expect that there will be some cross-clustering grouping of our work. But the point here is that public health is very broad and allows us to look at a number of these things.

Now, assessment as we define it is really the systematic collection of analyses and dissemination of information. It focuses on epidemiologic and laboratory research, investigations, and monitoring of community health problems and risk factors.

We also work towards policy development and basically taking what we have learned and promoting that from the translation of advancement in human genetics in terms of prevention and other opportunities. We do this through communication, through education, and through promotion of prevention for both clinical and population settings. Many of you may know this already.

We also then, because we have worked very hard at this, want to assure that this actually happens, moving from research and process to actions and then to being accountable for what gets done.

We do this through bolstering the public's confidence that this information is used appropriately and that the services we do meet agreed-upon goals for effectiveness, accessibility, and quality in research. We look also at how to assess that to make sure things are happening. We do this through a clear evaluation methodology and then quality assurance and quality control.

Then we look to ways we can work together to enforce laws and policy standards and to assure that we have the ability to get this done through the development and assurance of a competent work force.

In our policy questions, then, given that broad area, we want to really nail down what to do. So we have questions about the characteristics of the diverse systems of health care, how management and delivery influence the provision of genetic tests, and then, subsequently, how clinical or preventive services work.

We also were asking what are the leading opportunities and responsibilities for public health systems to contribute to the development and implementation of the new genomic knowledge and technologies to improve health, to prevent disease, and to address health disparities.

Specifically, we want to drill down to look at a couple things. First of all, there are the opportunities, challenges, and benefits of incorporating genomics into existing and future public health investigations and surveillance systems to advance knowledge.

There are also opportunities and responsibilities for incorporating evidence-based genomics and knowledge and technologies into public health programs to improve health and prevent disease, the actual application of this work.

We also wanted to look at the public health infrastructure and to partner, we believe. Part of our major focus in public health is collaboration and working within and across healthcare delivery systems, employers, businesses, communities, academia, media, and others, particularly consumers.

We wanted to also know what steps can be taken to address ethical, legal, and social issues in public health genomics research and practice. Drilling down, then, we want to know how does informed consent for DNA testing in public health differ from informed consent for other public health services and in clinical practice. Dr. FitzGerald brought this up. It is a clear issue because our question is, under what circumstances is new consent for archive specimens needed also for public health investigation.

We wanted to know what are the immediate and long-term benefits and risks of population-based disease registries, as well as how can concerns about potential stigmatization of the population groups result from research on testing programs be addressed.

We wanted to know what policies should be in place to share large amounts of data collected through gene, environment, and disease association studies, and we want to look at emerging concerns as technologies evolve. Will it become possible to test for multiple layers of biological challenges which reveal chinks in the bodily integrity before classical clinical symptoms emerge. Will advances in technologies and knowledge shift current conceptions of injury in toxic tort suits or the preexisting condition exclusion in GINA.

We also wanted to know what tools are needed to understand how genes and environmental factors, physical and social, interact to perturb biological pathways and cause injury or disease. How does the federal investment in genomics encourage translation into population health benefits. Is it cost effective to tailor interventions based on genetic information.

Lastly, what steps must be taken to assure a competent public health workforce with a sufficient knowledge base and skills to ensure that the appropriate use of genetic information to promote

SACGHS Meeting Transcript  
December 2, 2008

health and prevent disease, as well as to educate the general public to be informed consumers of genomic applications.

Given that, we wanted to know how can the public health agencies prepare the workforce and their constituencies to ensure that information about gene-environment interaction is used appropriately.

So, how to get there. For short-term actions, we believe we can organize sessions such as SACGHS meetings to expose the field of public health to genomics policy questions associated with advances in understanding gene-environment interactions and for in-depth discussion of the potential for genetic and genomic testing to exacerbate and lessen health disparities. Thus, the work with these clusters.

We believe that we can perform a systems review of relevant agencies to assess mechanisms that are already in place or can be in place to disseminate information about the distribution of genotypes in different populations and to assure effectiveness, accessibility, and quality of services.

We also wanted to look at the potential of using SACGHS as a forum to promote collaboration within and between DHHS agencies for efforts such as preventing the stigmatization of individuals, families, or populations at risk for or with genetic conditions and for implementing an assessment process that will provide guidance for how and when genetic tests can be used to promote health and prevent disease.

You can see our focus is on getting the work done. Again, we suggest brief reports on selected public health topics such as the impact of genetic and genomic testing on health disparities, how characteristics of different healthcare systems influence provision of genetic tests and subsequent clinical provision of preventive services, building a competent public health workforce to ensure appropriate use of genetic information to promote health and prevent disease, or whether it is cost effective to tailor interventions based on genetic information.

Of course, like everyone else, we really believe that this needs to be looked at very much in-depth, particularly at issues related to public health genomics in the areas of disparities, gene-environment interactions, and population-level testing. We left off, I think, workforce development.

DR. WISE: Comments, suggestions, or questions for Joseph?

[No response.]

DR. TELFAIR: It is clear. What can I say?

DR. WISE: We will have time to come back to these issues and discuss them both more globally but also in greater depth.