

**Update on SACGHS's Draft Report on the Policy Issues Associated with Undertaking a Large U.S. Population Cohort Project on Genes, Environment and Disease**

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DR. TUCKSON: Okay. Thank you for joining us and everybody is back on the committee. Can we focused again?

Now you know there was a technical glitch with the satellite otherwise you know I was ready to start exactly as promised at 4:15 so don't think that on break you guys can come back in late and I'm not running a tight ship. All right.

Now, in March of 2004, we identified large population studies as a high priority issue warranting our attention as the committee was reminded this morning when we looked at our list of strategic issues.

Our inquiry on this issue has also been shaped by a request from the NIH Director, Dr. Zerhouni, that we identify key policy issues associated with undertaking a large U.S. population cohort project on genes, environment and disease, and provide advice on the scientific—this is very specific language, especially for the new folks, I want you to lock in on this—provide advice on the scientific, public and ethical processes and approaches that might be used by HHS policy makers to make optimal decisions about undertaking such an effort. A draft report and recommendations were prepared—you might want to mute your mike for just a second in North Carolina. Thank you.

A draft report and recommendations were prepared and reviewed at our last meeting. I would like to thank Hunt Willard, chair of the LPS task force, and all the task force members, Sylvia, Chira, Kevin, Debra, Julio, Joseph and, the ex officios, Ellen Fox from DVA, Allen from NIH, and Maureen from CDC, for all their hard work in preparing and revising this draft to reflect our discussion at the March meeting.

A copy of that revised draft report is in tab 6 of your briefing books.

At our March meeting we also made decisions about the public comment process. I want to commend the task force for their efforts to make outreach as broad as possible. The draft report was released for public comment on May 22<sup>nd</sup>. This slide that's up right there gives you a sense of the efforts that have been made to solicit this public comment. The report along with a call for public comments was posted on the SACGHT's website May 22<sup>nd</sup>. You see the site. On the say day we mailed a "dear colleague" letter with the report to over 1,000 individuals and organizations. We notified selected media organizations to the NIH Office of Communication on June 7<sup>th</sup>. Last week we were happy to see in Science magazine a brief mention of the report. You'll find a copy of that in your table folders.

Announcements were also published in the Federal Register, the official government publication, and the NIH Guide for Grants and Contracts Notice, which reached a significant portion of the scientific community.

You'll find in your table folders a list of all the mechanisms that have been used to disseminate the report and the request for comments.

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We have asked the public to submit their comments on the draft report by July 31, which means there is time to do more outreach. So if you all know somebody that we didn't get, somebody you think is important, the train, while it left the station, ain't completely gone where it's going.

I encourage everyone here and all of you participating via the web cast to submit comments. I urge you to stimulate interest in the report.

As we continue to the public comment solicitation in our efforts to identify the policy issues around large gene-environment projects, we thought it would be helpful to learn more about the environmental components of gene-environment studies.