Data Collection on the Public Health Impact
Scott Bowen

MR. BOWEN: Okay.

Well, on behalf of CDC and the working group, I'd like to thank you for this opportunity to report to the committee about data collection efforts. Given the current lack of information regarding public health impact, we have been working actively to collect data about direct to consumer marketing of genetic tests, including levels of awareness among the general public and among practicing physicians.

At the national level, CDC is collecting data using the Health Style Survey in late 2006, which is targeted at consumers, and also the Doc Style Survey, which is comprised of primary care physician respondents.

Questions will include knowledge of various genetic tests available and the type of media by which that knowledge was gained. Also physicians are also going to be surveyed about the number of patients who asked about these tests and who actually brought such tests results to them.

In addition at the state level through mutual encouragement, three of the CDC funded capacity improvement states have added questions regarding direct to consumer marketing of genetic tests to their behavioral risk factor surveillance system modules for 2006, including Michigan, Oregon and also Utah.

The questions will ascertain awareness of direct to consumer marketed genetic tests and usage of the tests.

Results from all of these efforts are expected by mid year 2007.

In addition, I'd like to mention, as many of you know, Myriad Genetics launched an intense media campaign, a five month media campaign, in 2003 to promote the availability of direct to consumer tests to detect the presence of BRCA1 and BRCA2 mutations to women in the cities of Denver and Atlanta.

CDC then conducted a study of the resulting public health impact using Raleigh-Durham and Seattle as control sites and the results were recently published actually this month in the Journal of Genetics and Medicine. The study found that after the campaign physician's knowledge did not differ between pilot and control cities on a statistical basis but that more physicians reported greater interest in tests among patients and that more physicians in pilot cities versus controls, 14 and 7 percent respectively, reported an increase in the number of times they ordered genetic testing for breast and ovarian cancer in the previous six months.

The researchers also concluded that given the complexity and limitations of genetic testing for risk of breast and ovarian cancer that the development and broad dissemination of clinical guidelines and education of physicians are needed. In fact, many of the physicians responded that they needed more information about available genetic tests and would like to know more.

So there's a lot of work to be done in this area but we are pleased that these efforts are moving forward.

DR. TUCKSON: Let me just make sure. I think that there was a subtlety there that I want to make sure that I am not missing. You looked at the results of direct to consumer advertising and picked up that the people who were—in addition to the consumer—it was the health professionals who were picking up on it and, therefore, were getting information—and ordering more tests but it wasn't clear whether or not that was a way of reaching—the direct to consumer was a way of reaching the physician audience or was it the patients coming in and bugging the docs?

MR. BOWEN: Primarily it was the patients coming in and asking the doctors about it. Maybe they mentioned family history or just that they heard about the commercial and were concerned about their risk. The survey was actually conducted on primary care physicians and so there is a proxy factor to consider for consumers.

It's also worth mentioning that Myriad also had a limited campaign directly to physicians in terms of workshops and things like that.

DR. TUCKSON: It just seems to me, by the way, though, that probably the most—one of the things I think that would be important to know is direct to consumer does hit the physician because it's in the air and they're not getting this stuff in other places. So this may, in fact—it could be parenthetically argued that these campaigns are a way of giving information to clinicians.

MR. BOWEN: Certainly. It's certainly true and we see the same thing in direct to consumer marketing of pharmaceuticals as well that there's—through heightened awareness and questions that physicians often report higher levels of knowledge about the product.

DR. TUCKSON: Great. Terrific. Thank you very much. We will follow this update with interest.

DR. HANS: Thank you very much, Scott. Just a quick question is that I know that your conclusions regarding the need for more clinical guidelines in that and I'm assuming that the CDC's work was done prior to the release of the United States Preventive Services Task Force recommendations regarding testing. I don't know if there would be any follow up from the CDC to see whether something like that—those—the implications of actually having the release of recommendations from a government agency would have had any impact further than the direct to consumer impact.

MR. BOWEN: I think it's a very interesting question. I think you're referring to their response with regards to BRCA1 and 2, the U.S. Preventive Services Task Force. And it would be nice to—it makes an excellent research question and something we'll look at.

DR. TUCKSON: And one last question from Emily.

DR. WINN-DEEN: So I just wanted to know if you were also going to do similar research on the Tell Someone Campaign that's currently running on HPV testing?

MR. BOWEN: We are not. However, if the states where the pilot is occurring—I'm not sure if that's a national campaign or a state-based campaign.

DR. WINN-DEEN: I don't know. It's running in California for sure.

MR. BOWEN: But if those states are interested in asking for our help, we would certainly entertain that.