

**Survey on Public Attitudes Toward Genetic Technologies and Genetic Discrimination
Question and Answer**

DR. TUCKSON: Any questions you want to ask? Let me just start. I think you ended with what I was curious about. The big picture is that the data has not changed significantly.

Do you have any mechanism or way to determine whether or not the awareness of the issues is any greater? Do people know any more about this field? Is the idea or the word "genetics" and "genetic discrimination" or "genetic legislation" or "confidentiality of genetics," are any of those things more in the brain of people regardless of how they may feel about it?

MS. WHITE: Awareness increased the top box. There was very little change in awareness when you look at the entire spectrum, from nothing, something, a fair amount, a lot, with the exception of the top box of a lot, which I think increased by about 4 percentage points, and it was a very small number to begin with, so that is fairly substantial and is a significant increase in awareness. It's very small, though. We're not seeing large numbers of Americans in terms of the increase, but it is a statistically significant increase in the number of people that are saying they've heard or read something. So that is certainly true.

Then the number of people that are mentioning genetic discrimination in particular has not increased in terms of proportion, but when you consider the fact that there are more Americans that are aware, it has certainly increased. If we were to work that back, there would be a slight increase in the number of people mentioning genetic discrimination.

DR. TUCKSON: So lastly on this, there are more people who are aware, but the percentage of people who are expressing significant concern is about stable.

MS. WHITE: Yes, the concern number is stable. I can look that number up from last year.

DR. TUCKSON: Take your time, because there's no way you could be prepared for which direction these questions were going to come.

MS. WHITE: I don't have all these numbers in my head, at least not yet.

DR. TUCKSON: There's no clock ticking.

MS. WHITE: Actually, it was exactly stable. I found it, exactly stable with the top box. There's a 1 point difference, but it's not statistically different.

DR. TUCKSON: Thanks.

We have Francis, and then you.

DR. COLLINS: Thanks. That's a very interesting and important survey. I'm particularly interested in the statistics about what people's view is toward the likelihood of employers discriminating, since certainly it's been the case that with the current discussion of legislation the employer provisions seem to be particularly areas where it's been difficult to completely get to resolution.

I want to ask, though, about the national databank because that's obviously something we talked about at some length yesterday. Do you have a way in your data of assessing the correlation

coefficient between the people who are most worried about who is going to have access to this information and what their response is to this question about the databank? Because I could imagine that that might be a significant reason for people not to be enthusiastic, because they're not convinced those protections are there. Can you comment on that?

MS. WHITE: Yes, that is absolutely something we can look into. I mean, we can look at regressions across a variety of different variables to see what's driving that concern, or at least driving the people who are saying that they don't agree with the initiative. I think the questions about -- we could look at it in terms of all the specific organizations that they think might discriminate against them, and I imagine there are probably other variables in terms of just their general favorability toward the idea. We can also look at it by their health status. I imagine that Americans that aren't as healthy might be more interested in something like that, because they're more aware of general clinical trials and issues like that that might be happening that could benefit them in particular. So we can certainly run all that and get back to you on what we find out.

DR. EVANS: I'm really interested in the 30 percent of people who have concerns that would prevent them from having a genetic test, because that's certainly in keeping with what we observe in the clinic, I think. I wonder, also given the level of mistrust of government, did you ask a question that said say comprehensive federal legislation is passed, would you still now feel that you wouldn't get testing, because if they mistrust government so much, are they going to be that reassured by legislation? I just wonder if you have any data that might address that.

MS. WHITE: We may have a question about that. When I mentioned that increased/decreased number, there were a few other questions that we asked along that line, and there may be a question in there that says if you are assured by law. Yes, we have a question that says what would happen to your interest if you were assured that by law no one could access your DNA information without your consent, and there's a 60 percent increase. So 60 percent say they would be more interested in genetic testing if they were assured by law.

DR. TUCKSON: Yes?

DR. FROHBOESE: Hi. Just a couple of quick questions. Can you refresh us about how you drew your sample, and when you say that you had to weight the results for ethnicity, what were the ethnic categories that you were looking at, and what was the actual rate of response among various ethnic categories?

MS. WHITE: Again, the way that most email research is done today is there are about six or seven that I would consider most reputable email panel providers, and Greenfield Online and Survey Sampling I would say are sort of the cream of the crop when it comes to doing Web research. All they do is develop samples in the same way that survey sampling was the leader in terms of phone-based sample, RDD. So they have both taken on developing email panels, and they have anywhere between 4 to 7 million people in their panel, and they manage the panel in terms of how they recruit people. They don't only get them off the Web. They do phone recruits. So they go to great lengths to try to make sure that they have a fairly good representative sampling of Americans in their panel. They also make sure that people aren't over-surveyed and that they're not looking at the same topics all the time in issues like that.

When we go to them and we ask them to pull a sample for us, we give them the most recent population estimates and say we want you to pull out a replicate, so a large number of people that would allow us to get a 20 percent response rate that looks like the U.S. population on key Census

demographic variables, the ones that I mentioned, and we go out to those. So in some ways it's actually more pure than what you can do with RDD in terms of phone, because you have a lot of control with who you mail out to. You know that it looks like the U.S. population on a variety of demographic variables, and also the interplay of those variables.

So you go out to those populations. But what happens with any type of research, really well known for mail but it's also happening with phone too, you have underrepresentation of higher socioeconomic groups via phone today. So what happens with the Web is that there are really just two groups that underrepresent, not in terms of our being able to represent them going out but in terms of their response rates, Hispanics and African Americans less so, but Hispanics, and also those Americans with less than a high school education. So what happens with those groups is we have to oversample them when we go out, and then when the data comes back, even when we set soft quotas around specific variables, there are always groups that just don't respond at the same rates that we'd like.

So the two groups here that we weighted by education and ethnicity, not surprisingly, is pretty much what we always have to do, and what we had to do was weight up the Hispanic population slightly. So I think it was like maybe -- I'm making it up. Maybe it was like 10 percent up to 14 percent, which looks more like the Hispanic population in the U.S., and also education. We had to weight up those less than high school. So at the end, what we know when we look at all the demographics once we've done that, they represent the U.S. population.

If we were not to do that and those populations were to hold different views, then the numbers would become skewed and we would not be able to feel confident that the U.S. population would respond in the same way. Does that answer all of your questions? Was there something else?

DR. FROHBOESE: No. Thanks.

DR. TUCKSON: Sylvia?

MS. AU: Christy, I just want to follow up on Jim's question, that 60 percent increase in people that would have testing if there were better laws. Is that 60 percent of the 30 percent that wouldn't have testing?

MS. WHITE: That's of all Americans. So we'd have to cross that to see how many of them would. But it shows that across all Americans, 66 percent of them would move themselves from one category to another category, or would be even more likely than what they told us they would say before. So we could cross that and see where exactly we see the movement.

MS. AU: And also, did you ask a question about general feelings about government and cross-match it with the databank and whether they would want government to do this? Because as Americans' opinions of government go up or down, does that affect your results?

MS. WHITE: No. That somewhat relates to Francis' question about employers, and I was saying that we would want to look at all of the organizations. I am sure there's a correlation between their perceptions of government and what they're saying here. I mean, it's a somewhat obvious thing, but it would be good to quantify that and know that. I remember that there's something like only 1 percent of the U.S. population that says they would want the government to have their genetic information. So when you consider that, that there's only 1 percent of people that want the government to have their information, and then it jumps up to 24 and even 30 percent if they

SACGHS Meeting Transcript
March 27-28, 2006

can see there's a benefit and it's anonymous, I'm sure that there's a real heavy correlation between those Americans.

DR. TUCKSON: One last thing on the high level on the African American or Hispanic. Was there, again, any statistical difference between their rates of concern versus the rest of the population?

MS. WHITE: I know, because I was looking into trying to figure out something on another question, that Hispanics are less concerned about their employers discriminating against them, but that's actually the only variable.

One thing I should say which hopefully won't come across as too defensive is that we actually just got this data out of the field, and as Suzanne can attest, she got these slides maybe yesterday. We spent all our time just cleaning the data, making sure it's correct in the top line, but there are certainly a lot of subgroup analysis that will occur as we pull together -- what will happen from this is we'll pull together what will be about a 150-page report, and there will be all the subgroup analysis for every question will be with each one. So I'd certainly be willing and happy to provide that section of the report that relates to these questions to you once we have it so that all these really very valid questions, questions that even I have, will be answered in there.

DR. TUCKSON: Well, this is terrific. I want to thank you. You've done a great service for us, including now we recognize even under great duress. So thank you.

MS. WHITE: Thanks.