

Survey on Public Attitudes Toward Genetic Technologies and Genetic Discrimination
Christy White

DR. TUCKSON: Let me start with Christy White, who is going to give us some of the data, and then Sharon Terry will follow up on public attitudes. What we'll probably do, Sharon, is have your presentation, and then I think it makes sense, we may take a few questions after that, and then we'll move to Ms. White, and then sort of see where we are.

So the staff doesn't think I can't read, we made a conscious decision to switch the order. So I'm not nuts.

MS. WHITE: Thank you. Well, thanks for inviting me back again. I'm sure most of you recall that I was here not that long ago talking about the data from the 2005 study. We've just completed the 2006 study, and one of the things that we talked about at the last meeting was adding some questions that would get at Americans' awareness of current laws and protections and their feelings about that. So we added a few questions to get at that.

I'm actually going to be speaking fairly briefly today for a lot of reasons. One, I've given you a lot of detail the last time I was here. Also, this data is just in. So although we've done a lot of analytics on it, we haven't really finished doing all of that yet. Most of the information also looks fairly stable, so there's not too much to report on that. So what I'm going to do is really focus on the new questions that relate to some attitudes towards the specific entities that they may be concerned about when it comes to genetic discrimination, their awareness of specific protections, their perceptions of those protections, and their feelings about what should happen with legislation moving forward.

Before I do that, I want to ground us in two key areas. One is the methodology that was used for this research, and secondly the current climate for genomics. The methodology that was used for this, as has been for the past -- this is now the third time that we've run this study -- we use a Web survey methodology. We talked to a random sample of 1,000 Americans over the age of 18. The sampling error for this is plus or minus 3, a 95 percent confidence level. So when you're looking at these numbers, we can be 95 percent confident that they would not deviate any more than 3 points from what you see up here, and that is actually the worst-case scenario, when the data is split 50/50.

The sample for this research was obtained from Greenfield Online. They're one of the largest email panel providers in the U.S. The outgoing sample was balanced to the U.S. Census on age, education, gender, income, and ethnicity. As is always the case, certain populations are more likely than others to respond. So when the data comes back, in some cases we need to weight the data. Very minimal weighting was required, but we did weight the data by education and ethnicity to make sure that when we're looking at this data we can be sure that it represents the U.S. population, adult population.

So what I'd like to do now is talk just briefly about the current climate for genomics. Since I was here last, the climate is fairly stable. The data from last year to this year has not changed significantly. We still see about a quarter of Americans being aware of being able to use genetic information to understand and optimize health. We also see more than half of Americans continue to hold favorable views toward using genetic information to understand and optimize health. We also see that close to half of Americans are interested in being able to use genetic information to understand and optimize their own health. So this is for their own personal use. So these numbers have changed very slightly from last year.

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We also know, in terms of the current climate, that concern with misuse is still very high. Seventeen percent, so about 1 in 5 Americans, is mentioning genetic discrimination as a drawback of genomics, and this is on an unaided basis. So without any prompting, when we ask them what are the good things about it, what are the bad things about it, 17 percent mention something about their information being misused.

DR. TUCKSON: Christy, one second. Let me just ask you, could you go back just for a sec?

MS. WHITE: Yes.

DR. TUCKSON: I just want to make sure. When you say one-quarter are still aware, does that mean that 73 percent are not aware, or did the others say not sure?

MS. WHITE: No. I believe the bulk of those that did not say heard or read a lot said that they have heard something. I think there's only a small number of Americans that are saying that they have heard nothing about using genetic information. We do have a follow-on question to this which asks them specifically what have they heard, and when you look at those responses, really predominantly what they're saying is they understand there's a link between genomics and health. They're not saying that they understand that they can optimize their health through use of their genetic information. So it's a very superficial understanding at this point.

DR. TUCKSON: If you're going to cover this later, stop me also. But when you say the 52 percent are favorable, again how do we infer the 48 percent? They're not unfavorable.

MS. WHITE: No. Fifty-two is the top two boxes on a 5-point scale, and then again the bulk of those are neutral. I have the numbers over there, and when we get to the Q&A I'll look them up and report back to you on that. But I'm fairly certain that it's probably less than 1 or 2 in 10 that are -

DR. TUCKSON: Good. I just wanted to make sure that I wasn't over-reading the slides. Thank you.

MS. WHITE: No. That's a good point.

So we also know that 66 percent are concerned about how their personal genetic information will be stored and who would have access to that information. Here it's really a top box of 44 percent is pretty considerable. Typically what you'll see is more of a bell curve distribution on questions like this. So the fact that we have close to half of Americans giving the most extreme answer that they could provide in terms of concern is something pretty remarkable that you do not see very often. Again, here you can't see the full distribution, but really only 9 percent are saying that they do not have any concerns about who potentially might access their information and what would happen to it.

We also know that 30 percent of all Americans say that this concern would prevent them from having a genetic test. So about 1 in 3 Americans are saying that they're just not going to go there if they don't feel that their information is going to be protected.

There are numerous entities that are implicated in terms of who might try to gain unauthorized access to their personal genetic information, and really there's not much deviation on these responses. So life insurance companies, government and health insurance companies were all seeing about 65 percent of Americans, again with the majority being in that extremely concerned

category, saying that they are extremely concerned that one or more of these entities might gain access to their information. Slightly lower, although still more than half of Americans, again, are saying that a bank or financial institution or their employer may gain access to this information.

DR. LICINIO: When you say government, who are you referring to?

MS. WHITE: It is not specified for them. We just say the government. There are other questions where we actually do start to differentiate between different government organizations, but this is one where we kept it just as the government itself.

DR. LICINIO: (Inaudible.)

MS. WHITE: Yes, although we'll see there's some positive information for him later.

Again, I think I talked about this last time, but I thought it was worth revisiting because the numbers are still high. The extent of their mistrust is pretty extreme, with 65 percent saying insurance companies will do everything possible to use genetic information to deny coverage, a similar number saying insurance companies will use information to deny coverage for drugs people need if their genetic profile indicates a low chance of responding. Also on a different type of question, we asked would your interest increase or decrease for a variety of reasons, and this was the information would become part of their medical record and obtainable by insurance companies. So 56 percent say if they knew that, that their interest would drop.

So moving on to protections, the question was asked, as far as you know, are there laws that currently protect the privacy of your genetic information, and you can see only 18 percent of Americans believe that there are currently laws that protect them. Twelve percent are holding that viewpoint that they feel confident that there aren't laws, but really 70 percent are just saying they don't know. They have no awareness of the current laws and protections that are out there for them in particular.

We did want to ask a few questions of those people who thought that there were currently laws for them. So first we asked a question about when it comes to genetic testing issues, would you say that current medical and health privacy laws are sufficient, or is more protection needed. So again, this is among that sample of people that said that they thought there were laws. Only a fourth of them believe that the current laws are sufficient. So we have very few people knowing that there are laws, and among those that know there are laws, the vast majority of them think that they are not adequate.

We also wanted to know who they thought the laws protected them from. So under current laws, which, if any, of the following groups or organizations are prevented from accessing or using your genetic information to discriminate against you? Again, this is among the small subsample of people that believe there are laws. Most of them believe that the protections are specifically for employers. About half said health insurance companies and life insurance companies. Fewer said the government, and about 20 percent said that the laws don't protect them against anyone in particular.

DR. LEONARD: Excuse me. Are you able to correlate the responder's state with whether there are state laws that provide protection or not?

MS. WHITE: We do have region, and we could look at that. This is such a small subsample of people, though. This is about 200 people, I guess, that answered this question, given the percent

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of people that thought there were laws. But we do have the state that they live in. We could look at it by that.

The desire for protections is very high. Seventy-two percent of Americans agree that the government should establish laws and regulations to protect the privacy of individuals. You can see that only 5 percent or 7 percent of Americans are actually disagreeing. So you've got three-quarters of the people agreeing, and the majority of those people who are not agreeing holding neutral views but saying that there should be protections for them.

We also looked at what they thought of the current situation that's happening. So we educated them a little bit and said to them that right now Congress is considering new legislation that would amend current federal health information and privacy protections to specifically prohibit employers from using employees' personal genetic information to make hiring decisions or to set insurance rates. Then what is often done in public opinion, we gave them two views and we asked them which view they agreed with more. So the first view was some people say that business owners are responsible and would not misuse their employees' personal genetic information. Therefore, the new law would only add costly and unnecessary burden on businesses to comply. You can see that only 15 percent agreed with that. The other side of the coin was other people say that without amending the current laws to explicitly prohibit employers from misusing their employees' personal genetic information, it's only a matter of time before they use this information to discriminate against some individuals. So you can see that 85 percent -- and this is of the entire sample now -- 85 percent of Americans believe that employers will use their genetic information to discriminate against them unless there are explicit protections in the law for them.

We also asked some questions about a national databank, and this question has stated that there's been a major public health initiative proposed to create a national databank that would include detailed DNA and environmental information on up to half a million individuals. This information would provide a powerful tool for scientists to understand the link between genes and other factors and specific diseases affecting millions of Americans. To what extent do you agree or disagree with this initiative?

The question I just read is on the bottom half of this screen, and we had a split sample. We asked one just the government, and then we wanted to see what impact there would be if we actually named a specific organization. So we named NIH, and you can see overall that interest or agreement with the initiative is fairly low, with about only a quarter or a third of Americans thinking that the initiative is a good idea. But the number does increase if there's a specific organization, specifically NIH being named as being associated with that.

What's on the top of this screen, there was another question that we had for tracking purposes which was a much more simplistic question which just asked should there be a national database. It didn't go into what the benefits of that might be, and again we see a similar response to that and similar numbers.

So those are all the things we covered specifically to legislation. I do have all of the data with me if there are questions you have about things that I spoke to last time in terms of general awareness, favorability, areas of interest. There's a lot of data in there about pharmacogenomics specifically and benefits they want for that as well. But again, the data has not changed substantially from when I spoke last time, so I wanted to focus just on the legislation.