The Genetic Revolution and the Meaning of Life: How Will Society Respond to the Explosion of Knowledge?

Congressional Briefing
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Transcript of Proceedings

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The Genetic Revolution and the Meaning of Life: How will Society Respond to the Explosion of Knowledge?

Congressional Briefing

Friday, June 7, 2002
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B-340 Rayburn House Office Building

Science and technology are advancing faster than society's ability to understand and cope with new discoveries. These sweeping advances in scientific and medical knowledge have also fostered changes in our social and cultural landscape. As a result, the current explosion of information and its social implications confront individuals and society with a complex array of challenges.

At the forefront of this knowledge revolution are the rapid advances being made in genetics. In 2001, the National Human Genome Research Institute completed a working draft of the DNA sequence of the human genome, a milestone in the never-ending pursuit to better understand ourselves and the wonder of life. The completion of the Human Genome Project is expected to comprise one of the most powerful and direct approaches to the study of a wide range of biological questions. It will allow researchers to identify genetic contributions to many common disease and disorders, such as diabetes, heart disease, and some forms of cancer. But in order to realize that potential, the accompanying ethical, legal, and social implications must be addressed. How will individuals, health professionals, and policy makers interpret, understand, and use the findings of this research? How will society react to information suggesting the possibility of group differences with respect to individual genetic risk for common, complex disorders? Three distinguished scientists will address some of the issues and concerns associated with this rapid increase in knowledge for society.

Speakers: Dr. Troy Duster, New York University
The Intersection of Molecular Genetics, Race, and Criminal Justice

Dr. Dorothy Nelkin, New York University
Emerging Legal and Social Issues in the Genetic Age

Dr. Susan Weller, University of Texas Medical Branch
The Intra- and Inter-Cultural Variation in Medical Beliefs

Moderator: Angela Sharpe, Consortium of Social Science Associations

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EXECUTIVE SUMMARY

The Interplay of Genetic Advances and Race

Troy Duster, Professor of Sociology at New York University (NYU) and Director of the American Cultures Center and Chancellor's Professor at the University of California, Berkeley, discussed the role race and ethnicity have played in health research funding policy as genetic knowledge has advanced. He explained that throughout much of the 20th Century, public consensus existed to fund research on the diseases that had the most widespread impact on the human population. These included smallpox, tuberculosis, and cholera. Genetic advances in the later part of the century, however, changed the way segments of the public viewed funding decisions.

As research made us aware that varied "gene disorders (occur) at different frequencies in different prime populations," ethnic groups began forming coalitions to support research efforts on 'their' diseases. As a result, NIH funding is now allotted in many cases at rates disproportionate to the frequency of a given disease in the overall population. Some of these constituencies, Duster noted, have been extremely successful in their efforts while others have failed to gain much political traction. Racial disparities have also carried over the field of pharmacogenomics, as the Food and Drug Administration has recently approved the first drugs aimed at helping individuals from specified races.

Duster next turned his focus to criminal justice policy and genetic profiling. He explained that in Great Britain scientific papers have been presented calling on the police to use DNA evidence to identify the most likely ethnicity of assailants. This would potentially allow the authorities to narrow any existing suspect list for a crime. And in New York City, former Mayor Rudolph Giuliani and former Police Commissioner Howard Safir proposed taking a DNA sample every time an officer stopped somebody on the streets. This sample would be compared to the Police Department's computer database of all entered DNA samples to identify matches. Duster explained that this would be highly problematic because of racial profiling issues and the disproportionate rates at which individuals of certain races are stopped. He also noted that former U.S. Attorney General Janet Reno put a stop to the plan and asked the city to create a task force to study the matter.

Social and Legal Problems Created by Genetic Advances

Dorothy Nelkin, Professor of Law and Sociology at NYU addressed *Emerging Legal and Social Issues in the Genetic Age*. She began by explaining that there has been a great proliferation in the number of publicly and privately held genetic and tissue banks. As tests that predict future disease become more common, insurers, employers, and a wide array of varied social institutions will seek access to these repositories for information about their prospective clients and employees. "Questions of access to these data and their confidentiality will be increasingly important in future years and they have not been resolved although they pose unprecedented threats to personal privacy," noted Nelkin.

Another major issue presented by genetic research is the conflict between presenting findings to assist the common good vs. maintaining secrecy to win extremely valuable patents. Nelkin explained that studies have found "that scientists delay publication of research results in order to protect financial interests and that those with access to biological materials are less likely to share them when patents are at stake." In addition, universities have, in many cases, changed their data sharing policies to protect licensing rights. This trend could easily delay the development of vital treatments for a wide range of diseases.

Cultural Variation in Medical Beliefs

Susan Weller, Professor of Sociomedical Sciences at the University of Texas Medical Branch, opened her presentation by explaining that her research is focused on understanding to what extent individuals have the same or similar beliefs in different segments of society. To test this question, she collaborated with a team of researchers to measure AIDS knowledge of Latino populations in four diverse areas: Hartford, Connecticut; Edinburgh, Texas; Guadalajara, Mexico; and the Pacific Coast of Guatemala.

The study found that the responses in Connecticut featured the highest rate of homogeneity in responses (.72), followed by Texas (.62), Mexico (.55), and Guatemala (.48). Weller pointed out that homogeneity increased as prevalence of AIDS in the population also increased. The study also found that agreement was highest between those samples sharing geographic proximity; the Connecticut and Guatemala responses featured the lowest level of agreement (63% of the items, compared to 77% for Mexico and Guatemala or 76% for Connecticut and Texas). Weller concluded by noting that responses in all four sites were in line with biomedical assumptions about the disease and that variation in responses were more characteristic of less information rather than different beliefs.

Angela Sharpe, Moderator
Introduction
Consortium of Social Science Associations

Good morning. I am Angela Sharpe, the Associate Director for Government Affairs at the Consortium of Social Science Associations. Welcome to this morning's briefing, *The Genetic Revolution and the Meaning of Life: How will Society Respond to the Explosion of Knowledge?*

The decoding of the human genome has been heralded as one of the major scientific breakthroughs in recent history, with the potential to usher in a new era of human health protection. The genome's power and potential rests in the knowledge it provides and the information gained from increased genetic knowledge is of great interest to many.

Moreover, genetic profiles have the potential to affect the way we view ourselves and are perceived by others. And the growing number and use of genetic tests has many worried about discrimination due to inappropriate access to, and use of private genetic information. The list of concerns grows daily.

Before I introduce the speakers, I would like to acknowledge and thank Representative Connie Morella for providing the room and the COSSA staff, Howard Silver and John Wertman, for their assistance in putting together today's event. And on behalf of COSSA, I would also like to thank the W. K. Kellogg Foundation for its generous support of our seminar series.

Today, three social scientists will address some of the ethical, legal, and social implications of the genetic revolution. Dr. Troy Duster will examine the intersection of molecular biology, genetics, and the criminal justice system. Dr. Duster is a Professor of Sociology at New York University and Director of the American Cultures Center at the University of California at Berkeley, where he also has an appointment as Chancellor's Professor. He served as chair of the joint NIH/DOE Advisory Committee on Ethical, Legal and Social Issues in the Human Genome Project, also known as *The ELSI Working Group*, from 1996-98.

Dr. Dorothy Nelkin, also a professor at New York University, teaching in both the Department of Sociology and School of Law, will discuss genetic discrimination and privacy. Dr. Nelkin is a member of the National Academy of Sciences' Institute of Medicine. Her research examines science and law, science and society, and biotechnology regulation. She is the co-author of *The DNA Mystique: The Gene as Cultural Icon*, and *Body Bazaar: The Market for Human Tissue in the Biotechnology Age*.

And finally, Dr. Susan Weller, a Professor in Preventive Medicine and Community Health at the University of Texas Medical Branch, will talk about cultural beliefs. Using her research on AIDS and diabetes, Dr. Weller will discuss the importance and the implications for policy makers of understanding the knowledge, attitudes, and beliefs of the various populations before making policy decisions. She is currently working on a National Science Foundation-funded research project examining the cultural beliefs and health status of Type II diabetics.

We will begin with Dr. Duster and hold all questions until all of the speakers have completed their remarks.

Troy Duster

"The Intersection of Molecular Genetics, Race, and Criminal Justice"

New York University

I want to address the topic of the intersection of genetics, race, and crime this morning. But before doing so, I need to set the context. As Angela just indicated, the Human Genome project is concerned primarily with health and medicine. So I want to begin with a brief discussion about how the genetic revolution gets to the topic of race through medicine and health, and that will set the frame for the segue into crime.

For me the story begins with the fractured public health consensus, which the gene revolution ushered in. And here's what I mean: Prior to 1960 we could all agree that tuberculosis, smallpox, yellow fever, and cholera were not in the public interest. There was a consensus. That is, we were *all* vulnerable to smallpox and tuberculosis, no matter what our national origin, religion, or ethnic or racial identification. If cholera and yellow fever were in the area it meant something needed to be attended to in the most general public domain. Before this current era, it was much easier to achieve a consensus in terms of public health issues.

With the genetic revolution, however, we began to discover that gene disorders occur at different frequencies in different populations. We are either at higher or lower risk depending upon our population group. In Figure 1 you will see some data that indicate we discovered very quickly that – unlike tuberculosis or smallpox – we could now talk about cystic fibrosis as a disease affecting mainly those from North European ancestry; that Tay-Sachs was a disease for which Ashkenazi Jews are at higher risk than other groups, and so forth. This would have a direct impact upon the way in which we began to think about approaches and solutions to health issues.

Quite simply, before the genetic revolution, the public interest was in clear focus -- getting rid of smallpox. Now imagine that smallpox was mainly an Italian disease and tuberculosis was mainly an Irish disease, you might find differences in health care funding. And that is what happened. Once the genetic revolution started, we began to see health care funding mobilized around constituencies of ethnic and racial groupings. In Figure 2 you'll see health care funding just 35 years ago for three diseases: muscular dystrophy, cystic fibrosis, and sickle cell anemia, and the number of cases of each disease was about the same that year. But the research funding differences were sharp and dramatic: eight million dollars for muscular dystrophy, two million dollars for cystic fibrosis, while the total funding that year (1967) for sickle cell anemia was only thirty-eight thousand.

Figure 3 provides the data for what happened in just three decades. The capacity of different constituencies to mobilize in order to obtain research funding for "their disease" produced dramatic shifts in funding levels. For example, the National Institutes of Health budget for sickle cell sky-rocketed from a mere $38,000 in 1967 to forty-eight million dollars in 1997. The expenditures for Cystic Fibrosis were still higher, but this is a clear indication that an ethnic and racial basis for mobilization around "one's own disease" is a powerful force in setting research agendas. It happened as well with beta-thalassemia (at that time called Cooley's Anemia), because the Italians said "we want our disease funded." And it happened again with Tay-Sachs, because Jewish citizens demanded that "their disease" receive more attention with research funding.

But what happens to someone who happens to be a Zuni Indian? The Zuni have a CF mutation for which there is no genetic test, despite the fact that the risk for Cystic Fibrosis in this population is similar to that for Americans of North European descent. The explanation for this situation is quite simple, and relates directly to the matter of the capacity to mobilize politically and strategically. The Zuni are a small part of the population, both small in number and in political clout. They do not have the capacity to mobilize to get "their disease" tested and funded. This is the best example that I can provide of a short version of how the genetic revolution fractured the public

consensus – and propelled more and more thinking in terms of population groups and their specific health concerns and problems.

Ethnicities/Groups Primarily Affected by Disorders (USA)

Alpha-thalassemia	Chinese, Southeast Asian
Beta- thalassemia	Mediterranean
Tay-Sachs	Ashkenazi Jews
Cystic Fibrosis	North European
Phenylketonuria	European /Irish (especially)
Sickle-Cell Anemia	African-American
Adult lactose deficiency	Chinese, African-American
Duchenne M/Distrophy	Northeastern British
Cleft lip / palate	Native Amer / Japanese

L. Burhansstipanov, S. Giarratano, K. Koser, and J. Motgoven, *Prevention of Genetic and Birth Disorders* (Sacramento, California State Department of Education, 1987) 6-7

Figure 1

Health Care Funding, 1967

Number of New Cases:	Muscular Dystrophy	N = 825
	Cystic Fibrosis	N = 1,210
	Sickle Cell Anemia	N = 1,160
Research Funding:	Muscular Dystrophy	$7,940,000
	Cystic Fibrosis	$1,970,000
	Sickle-Cell Anemia	$38,000

MD funding 4x CF 200x Sickle Cell

Figure 2

NIH Research Funding, By Disease 1997

	No. Afflicted	Total Research $$	$$ Per Patient
Aids/Virus	775,000	$1,862,529,000	$2,403.26
Cystic Fibrosis	30,000	62,056,000	1,083.53
Sickle Cell	82,500	48,600,000	590.00
Breast Cancer	1,953,000	409,545,000	209.71
Prostate Cancer	968,000	94,614,000	97.70
Alzheimer's	4,000,000	314,159,000	78.45
Kidney Disease	3,512,000	203,677,000	57.99
Parkinson's	1,000,000	34,218,000	34.22
Heart Disease	13,670,000	285,150,000	20.86
Diabetes	16,000,000	313,334,000	19.58

Source: NIH, Centers for Disease Control and Prevention; figures for fiscal 1997

Figure 3

In the spring of 2000, there was a public ceremony at the White House announcing the completion of the "first draft" of the Human Genome Project. Francis Collins of the National Human Genome Research Institute and Craig Venter of the private consortium Celera, shared the platform with President Clinton. While Collins and Venter had many disagreements about strategy for completing the mapping and sequencing of the genome, including public versus private sector control, they did agree strongly on one matter at that White House press conference. They both said that the one thing we can be sure about is that *race is of no consequence at the DNA level.* When molecular biologists make such a statement, they quickly say what they mean, namely, that we are all 99.9% alike at the DNA level. If we randomly selected any two people in this room – African-American, white, Asian, it doesn't matter – and take a sample of their DNA, cut it open, put it on a computer chip and do the analysis, we would find that for every 999 points along the DNA, the two would have the exact same sequence of nucleotides (the famous CGTA that comprise the double helix). But then at about the 1000th point there will be a single nucleotide that is in a different location, called a single nucleotide polymorphism (or SNP). This pattern recurs throughout the whole genome of three billion base pairs. That is true for all of us, regardless of what we think we see on the surface, phenotypically, as "race."

Before the computer revolution, that was simply a hypothetical, without much in the way of practical application. Indeed, up until the last five years, the Human Genome Project was emphasizing what we had in common, and minimized our differences. The computer has changed all that, and we are now looking at the DNA in terms of human differentiation. The IBM "blue gene" computer can do 7.3 trillion calculations per second on the DNA. That is, we can now put the DNA on a computer chip (sometimes called SNPs on chips) and perform an analysis of the pattern configurations of those single points of difference at about every 1000 base pairs.

Thus, while there are three billion base pairs that are approximately 99.9% alike, that means there can be as many as 30 million points of difference, or 30 million SNPs. The metaphor of looking at the half-empty bottle or the half-full bottle is not quite apt. However, looking at three billion base pairs in which we are mainly alike (99.9 per cent) versus that .001 percent in which we are "different" translates into up to 30 million points of difference!! With the computer technology – we can now put a person's (or a group's) DNA on a chip and do a pattern analysis to see possible differences at these locations from someone else's DNA (or some other group's DNA). Thus, we might be able to see patterns in the DNA among all those who have breast cancer, or prostate cancer. Or, of course, we might begin to see patterns in the DNA SNP profiles that co-configure with ethnic and racial groups. So that's the background of the new attempts to re-link genetics to the old categories of race and ethnicity. This all comes together in the newly formed field of pharmacogenomics.

This new field seems to confront the conventional wisdom in molecular biology that asserts that race is of no consequence. In an article in *Science* (15 Oct. 1999), W.E. Evans and M.V. Relling tell us that these single nucleotide polymorphisms "differ in frequency among ethnic and racial groups," and indeed show marked differences. That is the background for the decision by the Food and Drug Administration to approve "the first ethnic drug" aimed primarily if not exclusively at African Americans. All this in a world in which we have said race was inconsequential? NitroMed is the company, BiDil is their drug. The Nitromed argument is that "blacks suffer heart disease a lot more, proportionally, than whites." They suggest that blacks have more of a deficiency of nitrous oxide. So they are aiming this drug at "black people." Race thus reenters the clinical scientific medical world with this attempt to deliver pharmaceuticals to a racialized population. This rescues talk about ethnicity and race at the DNA level, and has direct implications for what I want to say about its implications for criminal justice.

In part because the DNA revolution has been enhanced by new computer technologies, using computers to assist us in finding patterns in the DNA, an extraordinary claim was made about eight years ago in Great Britain by

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Ian Evett and his associates. Evett claimed that by using DNA markers at about six to eight points of the genome, he could predict with 85% accuracy whether a particular strand of DNA came from a person of UK background or Caribbean background. For a police officer working the streets of London, Birmingham, or Manchester, that is a rather obvious proxy for race.

So the language has now been subtly changed: Rather than whether or not we can estimate the ethnic or racial origins of a piece of DNA, we are now able to ask the question of the probability of the accuracy of an "ethnic estimation" of the owner of a tissue sample of the DNA. We now infer the ethnic origin using short tandem repeats through the use of the computers. So that's where we are in terms of what I'll call the contradictions on the one end which embraces toxicology with respect to ethnic origins of "profiling" the stains.

Approximately three and a half years ago, then-Mayor Giuliani and then-Police Chief Howard Safir in New York City proposed to use these technologies to help them fight crime. They wanted the police to be able to use this computer-assisted technology to match the DNA of those persons stopped by officers with a national criminal database. Whitehead Laboratories, one of the big labs that had been involved in developing technologies for the human genome project, had produced a small device, about the size of a compact disc player.

When stopped by the police on the streets of New York, they could take a swab of your saliva, place it on this little device, go back to the computer in the police car, and then see if they get what's called a cold hit. That is, they can determine if the DNA matches some DNA on file at the national database.

We have long been familiar with the idea that the police can stop a driver, look at your license, then call back to see whether one has a lot of outstanding tickets or other violations. Well, this technology is what's coming to a neighborhood near you, in the near future -- the DNA cold hit. This is not only a possibility, it is a pilot study.

Some six in ten arrests in the United States are related to the drug war. For the last three decades, when the police make stops for a possible drug bust, they do so using a very selective lens. It turns out that there is a systematic bias in where the police will make those stops and arrests. In addition to selectively stopping certain drivers and searching them, the police have another strategy, what is called a "buy-and-bust" operation. The degree to which the police are stopping citizens based upon what is perceived as the phenotype as race is strikingly selective. The ratio of black to white stops is about seven to one in New Jersey, Maryland, New York, and California where we have the most data. Even though the amount of drug use is relatively common in both the white and black populations, the proportion of stops and arrests is at least six to one in many of our major metropolitan areas.

As we begin to increase the numbers of tissue samples, expanding our national DNA database from felons to misdemeanants to, increasingly, those merely arrested, we will see increasing distortions in the database by race. Imagine projecting this pattern into the near future, and what things might look like in the next decade. Fear of crime, concerns about terrorism, all these things are on our agendas and are now very much a part of our collective cognitive and emotional make up.

The computer is being used currently to try to provide a certain kind of genetic profile (SNP profile) of those with a particular health problem. A good example would be prostate cancer. A clinical population of those with this condition is sampled, and their DNA is collected. With the aid of the computer, all those in the sample have their DNA analyzed to see if there are any patterns or

Rather than whether or not we can estimate the ethnic or racial origins of a piece of DNA, we are now able to ask the question of the probability of the accuracy of an "ethnic estimation of the owner of a tissue sample of the DNA."

markers that differentiates them from a non-clinical population.

Just as we are currently trying to find SNP profiles of those with prostate cancer to focus better the hunt for candidate genes (to help explore the genetic susceptibility to this condition), there will soon be research programs searching for SNP profiles of rapists and murderers. The research strategy will be the same, namely, a researcher will obtain the DNA samples of a group of convicted rapists or murderers, then try to find patterns in the DNA markers. Computers programmed to look for patterns at 7.3 calculations per second across 3 billion base pairs will find patterns. Whether there is anything more than a spurious correlation is of course, the question.

More ominous is the fact that the extraordinarily imbalanced distortion of the database by race means that we will begin to see spurious correlations by race – as evidenced by the simple fact that the sickle cell gene is more likely to occur in Americans of West African descent than Americans of North European descent. Since more Americans of West African descent than in Americans of North European descent occupy our prisons – by a ratio of more than six to one – a finding that "race" plays a role in crime will be the 21st Century rendering of phrenology – a science that was popular during the last part of the 19th century, but which was clearly focused on correlation (bone structure and physiognomy of incarcerated criminals) without causation.

Again, it is important to note that SNP profiling will occur because computers will generate correlations. The naked human can not observe those patterns, but a computer can generate them – from those 30 million single nucleotide polymorphisms. They will find patterns just as Lombroso found patterns with the structure of the angle of the forehead of criminals in 1870 in Italy. Unless we're aware of the underpinnings of the biological revolution, we may come to believe that this technology really has "science" and evidence in it. We already know that racial profiling practices by the police are part of a systematic training program initiated by the Drug Enforcement Administration (Project Intercept), and that this has in turn produced a sharp increase in the rate of arrests and imprisonment for persons of color.

The connection between genetics, crime, and race will come in a way that will be a blindside to the nation. We will initially be drawn inexorably to the high technology of genetic markers for such high profile crimes as sex offenders who abuse children, then segue to an attempt to get markers for violent offenders, homicides, and then the slope to burglars, car thieves, and parking violators. We currently are witnessing a geometric expansion of the national criminal DNA database – with lots of people who are committing crimes of property included in the database. Recently, even those who are merely arrested, and some with very minor misdemeanors are being included in the national DNA database.

The connection between genetics, crime, and race will come in a way that will be a blindside to the nation.

I raised this question in a televised conversation and debate with the former police chief in New York. His response to my concern about the subterranean racial bias in the current database was "put everybody into the database." There was also a *New York Times* opinion piece about two months ago by a professor of law at Yale that argued along similar lines. Let's get everybody's DNA. That will solve the problem. But that is a fool's gold. Why? Because if the arrest patterns continue along racial lines, the system can only generate a "cold hit" from those who are caught in the lens and apparatus of the criminal justice system.

I will conclude with an example of how the selective artillery of the drug war – aimed primarily at blacks and Latinos, will always bias the capacity of the "cold hit" to be unfair and unjust. In 1989 the police executed a successful raid on a fraternity house at the University of Virginia campus. They arrested several fraternity boys for cocaine possession, an amount sufficient in size to indicate re-sale as the goal. However, rather than applauding the

raid, the print and electronic media around the country chided police for wasting the taxpayers' dollars. The argument was that this was a waste of resources, because instead of this raid, they raised the question of why the police were not going after real criminals. In the ensuing thirteen years there hasn't been a single drug raid on a college campus – or at least one that has caught the attention of the national media.

This means that even if the fraternity is engaged in illegal drug sales, unless the criminal justice system is aimed in that direction, it cannot produce a "cold hit" for members of that group. Instead, by concentrating primarily on drug buy-and-bust operations within minority communities, only members of those groups are subject to arrests and the saliva test for "matching DNA" that constitutes the "cold hit." So even if we are all in the database, what this will still miss is the selective pattern of those "committing crimes" who are outside the scrutiny and purview of the police.

Again, unless we understand the limits of these technologies we will be befuddled by what appears to be the equivalent of a 21st Century phrenology, but now dressed up seductively in computer-generated DNA garb as the latest science.

Dorothy Nelkin

"Emerging Legal and Social Issues in the Genetic Age"

New York University

As Troy has indicated, genes are the sequence that can be replicated and manipulated and genetic tests today are able not only to detect identity but also predict a growing number of diseases in asymptomatic people. They are of interest in both clinical and also in non-clinical context. While the genetic revolution is going to clearly yield benefits it is also presenting legal and ethical dilemmas and that is what I have been asked to talk about.

What I will do is present a brief overview of four problems that are likely to emerge in the years to come. These include problems of privacy posed by genetic testing and the banking of DNA information. The problems that occur as promises about therapeutic solutions lag behind diagnostics. The questions of patenting property and conflicts of interest. And finally, the threat of a future surveillance society.

Molecular biologist Leroy Hood predicted that people will soon be carrying plastic credit cards containing a read out of their personal genome. Your entire genome, he said, will fit on the card. Human tissue, when subjected to DNA analysis, can reveal intimate and detailed information about a person. The information and the body tissue that reveals such information is being stored in a growing number of public and private repositories. Gene and tissue banks are proliferating, organized by law enforcement agencies, the military, newborn screening programs, and hospitals.

In the United States alone, more than 282 million archives and identifiable tissue specimens are stored in repositories. Nearly every one of us has our DNA on file. Questions of access to these data and their confidentiality will be increasingly important and they have not been resolved although they pose unprecedented threats to personal privacy.

Now to understand these threats, we must consider the values that social institutions could place on genetics; that is on predictive information. Insurers, employers, the courts and other non-clinical institutions, for example, immigration authorities, motor vehicle bureaus, organ transplant registries, adoption agencies, sports teams, and the military have much to gain from using genetic information to predict the future health and behavioral status of their clients.

Considering the rapid development of genetic diagnostics, there is insufficient discussion, I contend, about questions of access to biological information and few laws that would protect privacy.

I'll just give you one much repeated example: genetic information is valued as a means to justify employment decisions, identifying those who are predisposed to genetic disease can be a cost effective means for companies to control absenteeism, reduce compensation claims, and limit future medical costs. There are some protections under the Americans With Disability Act. Studies of genetic discrimination in fact find that people who are asymptomatic but identified as predisposed to a genetic condition have been barred from insurance, drivers' licenses, adoption, or employment because of their genetic labels.

The significance of this information rests of course on how well it could be used. We are likely to see the emergence of companies that store profiles just as today they store information about shopping habits and sell the data to interested parties. Yet, there are many uncertainties and even as tests increase in accuracy and extend the range of what they can predict, questions of interpretation will remain.

How do we balance social and institutional interests against the privacy rights of individuals when these interests collide? Considering the rapid development of genetic diagnostics, there is insufficient discussion, I contend, about questions of access to biological information and few laws that would protect privacy.

Let me turn to the second issue, the problems when promises fail. As I'm sure you all know the genetic revolution has been promoted with extraordinary hype. Think back to the past disputes about nuclear power. Just as nuclear power was to solve the world's energy problems, so genetics have been promoted as the way to solve problems of health. But the reality is likely to be far more limited.

Tests are becoming available well in advance of therapeutic possibilities. Though scientists have been promising therapeutic solutions to genetic disorders since the early 1980s, very few gene therapies have yet materialized. If nothing can be done, why be tested given the issues of privacy that I just talked about? And even if therapies do emerge, there will be significant problems of distribution. Who is going to have access? Will the products developed be available at a manageable cost?

As early as 1987 the director of a biotech firm proclaimed "that the future lies in genetic testing." By the millennium, with the proliferation of patenting and a promise of corporate profits for marketing genetic tests it became clear that this prediction was on target. And the problematic implications for scientists, their research, and their human subjects were already beginning to emerge. The rush to patent cell lines is going to raise increasing problems for clinicians. What are the implications of patenting for the public trust in science and medicine?

Entrepreneurial interests will ultimately increase the cost of medical treatments and may lead to cover-ups about possible risks. They raise questions about the non-scientific interests -- the investments and profits that are driving some areas of genetics research. Are commercial interests and financial incentives overriding ethical considerations in the competitive context driven by potential profit? Will adequate attention be given to possible side effects of therapeutic procedures?

Finally, the possibilities of DNA identification have raised the risk of a surveillance society, something in all of our minds for obvious reasons these days.

The prospect of patenting can also impede research by reducing openness and data sharing, delaying publication advising the direction of research for short-term commercial goals. There's been a number of surveys over the last five years finding that possibilities of commercial gain influence the type of research that scientists choose to do. They found that scientists delay publication of research results in order to protect financial interests and that those with access to biological materials are less likely to share them when patents are at stake.

One important side effect of the genetic revolution and commercial backing for this research has been the remarkable changes in universities and their research practices. The possibility of profit will change the way that science is done and how universities operate. This will have implications for conflicts of interest, secrecy in science, and the organization of academia.

Finally, the possibilities of DNA identification have raised the risk of a surveillance society, something in all of our minds for obvious reasons these days. I'll try not to overlap too much with Troy's presentation a few minutes ago. DNA fingerprinting as we know has become a compelling means of both identifying criminal suspects and also exonerating those who were wrongly convicted. But this technology can also be abused.

In some places, police have organized DNA dragnets insisting that potential subjects, people for example in the vicinity of a crime all submit samples for DNA analysis. Though consent is required, refusal is seen as evidence of guilt. In the future, DNA fingerprinting is likely to be expanded beyond the criminal justice system, for example, as a tool in immigration policy. Given anti-immigration sentiments, testing of immigrants could expand and be used to reveal not only a person's identity but also present and future health status.

Databanks that can be easily accessed for purposes of identification are a useful means to implement legitimate policy goals. When I talk about this, people often say, so what's wrong? Why not? After all, you know, we wouldn't mind. We're not the problem. But they challenge civil liberties which I believe are relatively important and affect us all. With new developments in the science of behavioral genetics, one could envision the use of genetic tests to identify those people who might be predisposed to violence and the taking of preventive measures before the occurrence of actual violent acts. I collect media and popular culture articles as part of my research and there are lots of such proposals in the media.

What then is a legitimate reason for collecting DNA data and who should have access to the information? How should we respond to recent proposals for smart cards, that is identity cards that include genetic information and gene chips implanted under the skin to track individuals?

Well, what I've tried to do is to give you an idea of the diverse implications of genetics and the issues that I believe are going to warrant continued analysis over the coming years. Thank you.

Susan Weller

"The Intra- and Inter-Cultural Variation in Medical Beliefs"

University of Texas Medical Branch

Good morning. We're gong to change gears a little bit now and talk about the whole person. I am going to describe some studies that we've done looking at intra and inter-cultural variation beliefs. That means basically within and between groups.

There are three ways to describe beliefs systematically. Given a series of questions on a single topic, beliefs may be described by: one, a very simple intuitive way of simply aggregating people's responses and taking the modal response, which is what we say in statistics, or the majority response, across people to estimate what they believe. A second method is slightly more complicated. It also uses aggregated responses but additionally incorporates agreement across questions. This method is based on reliability theory from psychology that's been around since 1904. There is a mathematical relationship between the level of agreement and number of raters and the reliability and validity of an aggregation.

A third method, which is a relatively new one, is called the cultural consensus model. While all three of these methods are based on an aggregation, each one adds a little bit more information into it and comes out with a little bit more data. The cultural consensus model is an aggregative method but it also provides an estimate of how much each person knows the cultural beliefs and provides estimates of the answers to the questions. The cultural consensus model is a formal mathematical model that is derived from axioms. It encompasses a situation in which researchers do not know how much the informant knows about the cultural beliefs and also that the researcher does not know the answers to the questions, so the goal of the research is to try to find out what people believe about a particular topic. The model then provides an estimate of what each person interviewed knows about the beliefs and an estimate of the culturally correct answers.

What I am going to talk about, the questions guiding some of these research projects that I'm going to summarize, is to what extent the individuals have the same or similar beliefs in different segments of society. Are there shared beliefs within different sub-segments of society? And then to what degree are beliefs shared across different groups? A basic underlying question is: are we operating with facts or are we working with stereotypes about what different people believe and think? Understanding knowledge, attitudes, and beliefs within and between different subgroups is important to making appropriate policy decisions.

Let me start by summarizing one study that we did about AIDS. The background and the motivation for this study was that AIDS disproportionately affects minorities. That means that there are more cases of AIDS among Hispanics and African Americans than they are represented in the population. Furthermore, national surveys of knowledge, attitudes, and practices conducted by the National Center for Health Statistics indicate that minorities, I'm going to talk about Hispanics but this is also true for African Americans, that these groups tend to consistently score lower on knowledge tests about AIDS. What has been unclear about these results is whether what we're looking at is a difference in knowledge about AIDS or whether these groups may have different cultural beliefs about the disease.

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One possibility is that people may answer questions incorrectly because they have different cultural beliefs. For example, many Latinos may believe that if you walk on a cold floor you can get a cold. Now while this is

biomedically incorrect, the belief is part of a larger belief system where colds are related to a balance between hot and cold elements. Thus with regard to AIDS, people could provide responses that are wrong biomedically because they hold an alterative belief system.

In this study, and in a series of studies, we collected interview data regarding perceived risks, causes, symptoms, treatments, and things that can happen to you with AIDS or HIV in order to describe Latino beliefs about AIDS. Our point of view in beginning the research is not to find out what people know and don't know about the biomedical assumptions of the disease, but instead to look at it from their point of view about what they believe about the disease.

For this study, interviews were conducted in four very diverse sites. We focused on Hispanics and interviewed people in two U.S. sites and two international sites. The first U.S. site involved Puerto Ricans in Hartford, Connecticut and the second focused on Mexican Americans in Edinburgh, Texas. This is on the border and is one of the three poorest communities in the United States. The two international sites were Guadalajara, Mexico, a very large modern city in Central Mexico and on the Pacific Coast of Guatemala, in the rural part of the country.

Now I would like to underscore the diversity across these communities. They all share to some degree language similarities, but Spanish does not directly translate across all of these four communities as there are regional variations and idioms. Also, the rural community in Guatemala is extremely poor. There are dirt floors, no running water, and the average education is one year. That means that the majority of the people, two-thirds of the people are illiterate and they work on plantations.

Questionnaires were developed from initial background descriptive interviews at each of these four sites where people described what they knew about AIDS, about what causes it, who gets it, what it looks like in terms of symptoms and what you would do about it. From those interviews a systematic structured interview was created for all sites. The purpose of the study was to see if people share a coherent set of beliefs or information about AIDS at each of these sites and then to see the degree to which those beliefs may be shared across sites.

The second thing that we found was that the beliefs were shared across these very diverse communities . . . commonality tended to concentrate on transmission, that is, the risks and causes of AIDS and on the consequences of treatment of AIDS and

The findings were actually quite striking. The first thing that we found was that there was in fact a single shared set of beliefs at each site. Now this is quite striking because first of all there wasn't any reason to assume in, for instance, Guatemala that they should have coherent formed beliefs about AIDS, but in fact they did. What we found was that the homogeneity in the responses or the strength of the belief system varied so that it was strongest in Connecticut. Connecticut was stronger than Texas. Texas more than Mexico. Mexico more than Guatemala. As Figure 1 shows us, this ordering of the consistency of beliefs paralleled the prevalence of disease in those areas and also the fullness of the description of AIDS in each of those communities.

The second thing that we found was that the beliefs were shared across these very diverse communities. In Figure 2 you'll see that there was about a 55% sharing of the total description of AIDS across the four communities. And even within the shared belief system that we found across all these communities, there were some differences. First of all, commonality tended to concentrate on transmission, that is, the risks and causes of AIDS and on the consequences of treatment of AIDS and somewhat less on symptoms.

Descriptions and beliefs also were in agreement with biomedical assumptions. So, for example, some of the things we found in what people believe in the four Latino samples, is that HIV is caused by a virus; that it's transmitted sexually from multiple sexual partners, from shared needles, from a pregnant mother to her unborn

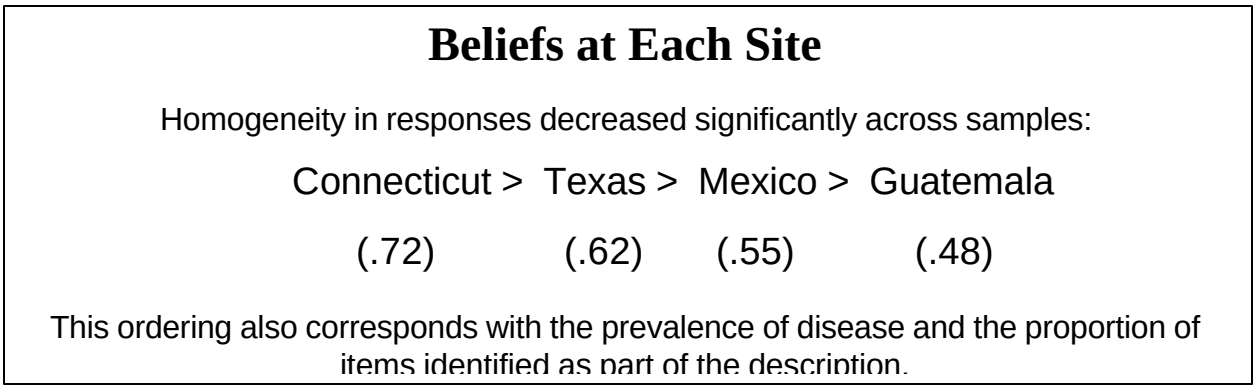

Figure 1

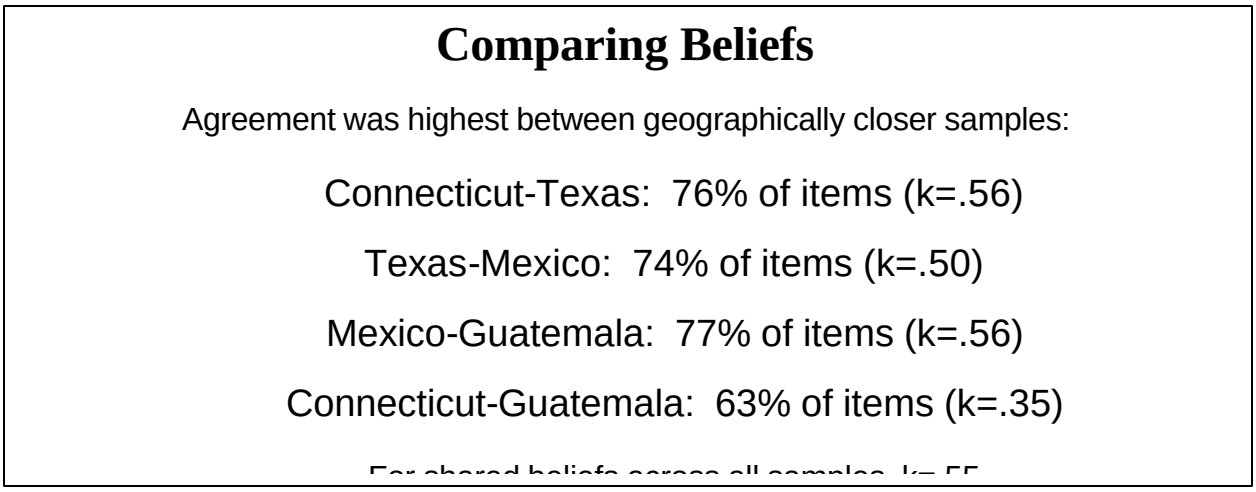

Figure 2

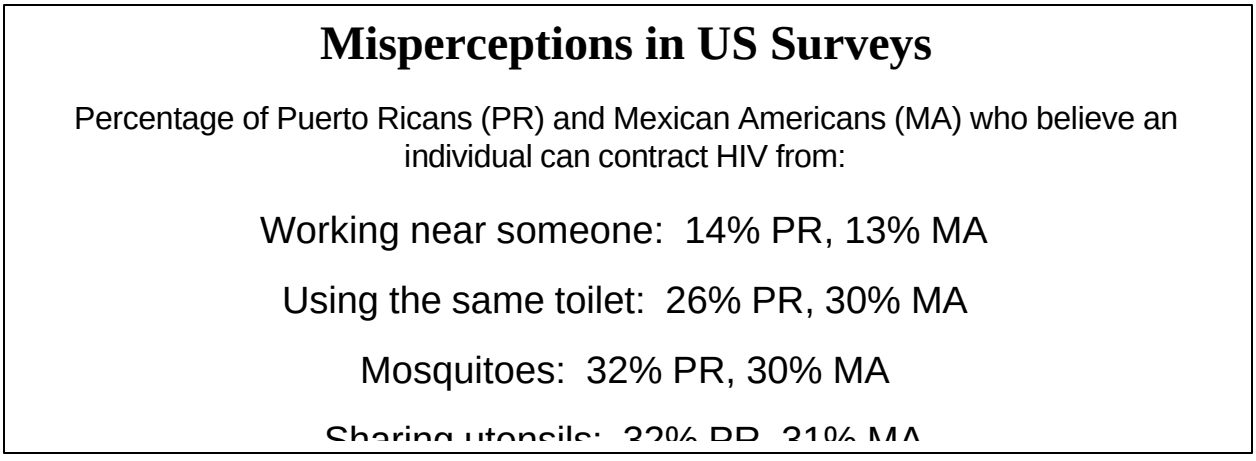

Figure 3

child, that condoms can reduce risk, that homosexuals and prostitutes are at risk, that you can get it from contaminated blood from a blood transfusion, and it is not transmitted from being near someone who has it or wearing their clothes. Nor can it be transmitted from unclean water, parasites, or mosquitoes.

With regards to the treatment, they believe that there is no cure for it; that you will die from it if you get it. Once you get it, you will only live a few years. You may die sooner without medicine and that the only appropriate treatment is a doctor or a hospital. They did not believe that homeopathic medicine was helpful nor were herbalists, herbs, teas, home remedies, or prayer. Now this last finding is important because one of the stereotypes often about Hispanics is that they tend to use more folk remedies.

Now with regard to the symptoms, we found similarity but a very distinctive pattern in the reporting of symptoms across sites. There were symptoms reported by all four of the samples that roughly describe AIDS, and there were symptoms mentioned by only three samples, and some by two samples and an extra long list of symptoms listed by the Connecticut sample. We found a pattern consistent with the level of AIDS in the community; that the more AIDS there was in the community, the more detail was reported in the descriptions of AIDS.

We then interviewed an additional sample, a white middle class sample in Tampa, Florida to study the degree to which these beliefs may be just Hispanic beliefs or Latino beliefs. What we found in this group in Tampa, was again there were shared beliefs within the sample but also that the beliefs were shared across all five samples.

. . . what we found is that the increased variation and responses from Connecticut to Texas to Mexico to Guatemala is a pattern characteristic of less information rather than different

So there were no meaningful differences between rural Guatemala; rural Texas; Hartford, Connecticut; Guadalajara, Mexico; and Tampa, Florida. There was a single model regarding AIDS and that model tended to converge on the biomedical model. One thing of note that we did find and that was only in the middle class sample was that people thought that prayer, a positive attitude and healthy eating would be helpful treatments for AIDS.

So in summary what we found is a striking similarity in beliefs across the diverse samples. Again, I want to note that the average education level varied from on average one year at Guatemala to seven years in Mexico, 10 years in Texas and Connecticut, and 12 years in Tampa. The respondents' age was fairly consistent across the samples except that the Tampa sample was older.

What also varied is the community prevalence of AIDS and we've estimated that in two ways. One is we asked in a survey do you know someone with AIDS and you can see the general relationship is that more people in Connecticut know someone with AIDS than in Texas and Tampa and even fewer in Guatemala and Mexico. Other estimates of AIDS prevalence from the CDC show one case per 100,000 in Guatemala up to higher rates in Connecticut. It's 50 per 100,000 in the State of Connecticut but 70 per 100,000 among Puerto Ricans.

The second finding was that the beliefs converged on biomedical assumptions for the disease. Misconceptions have been identified in the U.S. surveys, for example, you can get it either working near someone,

using the same toilet, from mosquitoes and sharing utensils. As you'll see in Figure 3, these error rates have varied between 14% for Puerto Ricans and 13% for Mexican Americans. What we found is that although these are high error rates, these are not shared beliefs about AIDS. These are in fact, errors.

In our own study, what we found is that the increased variation and responses from Connecticut to Texas to Mexico and Guatemala is *a pattern characteristic of less information rather than of different beliefs.* What this is, an analogy is like they're shooting at the same target but they're getting fewer bullseyes. A second thing is that the *distribution of knowledge parallels the prevalence of the disease*. It suggests a diffusion model for beliefs as well as for the disease. Greater variation in responses may indicate areas in which population opinion may be more malleable and perhaps sensitive to different types of targeted information for educational intervention.

In another study related to this, we did a similar design in the study of beliefs about diabetes. Diabetes is highly prevalent among Latinos and given the high prevalence and severity of diabetes it's surprising actually how little is known about their knowledge, beliefs, and practices with regard to this disease.

In the United States, Mexican-American and Puerto Rican adults are twice as likely as non-Hispanic whites to have diabetes. They have more end stage renal disease than non-Hispanics. Their mortality is twice as high and it's important within this community to understand the illness within the context within which illness occurs. Many Latinos will develop diabetes and norms about illness behavior are based in family and community so what people do about the disease is based on what they believe about the disease.

The findings from this study again indicated that there were shared community-held beliefs about diabetes. Each of these four samples showed sufficient consistency in responses to indicate a single shared belief system about diabetes. The second finding was that the beliefs were shared across these four diverse samples. Altogether respondents showed sufficient homogeneity again to indicate a single shared set across these diverse communities.

A third finding with relation to diabetes was that greater acculturation, this is for the U.S. samples, was associated with greater cultural knowledge about diabetes. The fourth finding was that the overall Latino cultural beliefs about diabetes were concordant with the biomedical model. Again the variation in responses tended to characterize less knowledge or experience with diabetes and not that beliefs were different from the biomedical model.

To summarize what we found in these studies of beliefs about AIDS and diabetes, findings indicated that the diverse Latino samples shared beliefs and that those beliefs were concordant with biomedical assumptions. The pattern of variation in responses was characteristic of less information and not different beliefs. And again it's like having a single target that we're all shooting at; but some people have better aim, more information, and are getting answers more concordant with biomedical answers.

What the findings also indicate is that it looks like there is an unequal distribution or access to information about these diseases. These are populations disproportionately affected by these diseases and they have less knowledge about those diseases. Finally, the findings indicate a communication gap between the biomedical technical community and the population at-large. Thank you very much.

Q & A

Deborah Olster, National Institutes of Health: This may be more a comment than a question. In terms of this genetic revolution that we are going through, it sounds like we are on our way to a scientific revolution. One thing that is often left out of the discussion which disturbs me is that just knowing what genes you have is sort of a tiny tip of the iceberg, and most diseases are polygenetic, if they have a genetic component, and certainly behaviors are going to occur because they have a polygenetic genetic component, and on top of that we have got this incredible interaction with the environment. Very broadly defined as the environment of the single cell versus the cultural, social environment, all of which can influence gene expression. My point is that nobody seems to be talking about whether or not your genes are expressed and where you go from there, and the complexity multiplies from that point. Why do you think that is left out of the discussion and if we put it back into the discussion will it mitigate some of these scary scenarios?

DUSTER: I am sure my other panelists have a response to that, but let me start. The rhetoric has changed in the last 15 years. If we go back to the late 1980s, Nobel laureate Wally Gilbert would pull a compact disc out of his pocket, hold it up, and say "In the year 2010 -- this is you!" This was an exaggerated and simple reductionist version of genetics and the power of DNA. Namely, it was the idea that you mentioned – that all we need to do is have our DNA on computer chips or CDs, and our physician would then be able to tell us our future health vulnerabilities. In the last five years that rhetoric changed a lot. Instead, we have begun to hear things like this: "When we finish Human Genome Project, it will only be a beginning of the real science." So while fifteen years ago, we were being told that the DNA was going to be "the code of life" – now the much more humble statements are being made that "we are only at the beginning – developing a tool that someday will produce improved health results."

Indeed, when they announced completion of the first draft of the human sequence map, most were surprised that there are only about 35,000 genes. This finding meant that proteins are playing a much more dramatic role. In this announcement two years ago there was the new language which signaled your observation, namely, that pharmacogenomics is the next "revolution." The new idea is that once we better understand the role of proteins, we will have the capacity to go to gene therapy – which is what Dot Nelkin said. The promise, always in the future, that once we get the next step we will have "the answers." In the last three or four years there has been a re-conceptualizing of the explanatory power of the DNA, and fewer and fewer people are buying into those early reductionist terms. But that was the long-winded prologue to my conclusion, which is that 50 years from now, when we look back, we will say that the biotech revolution completely distorted our understanding of the problem. All the billions of dollars sunk into this industry with the hope of breakthroughs in gene therapy – we are finding out increasingly that this is a blind alley. I would say even in five or 10 years you are going to find out biotech investments are going to be looking more and more like the accounting firms' exaggerations of profits.

NELKIN: Let me comment in a different way and offer another perspective. Genetic explanations fit with the impulse for dismantling the welfare state. You can blame diseases, blame behavior, blame social problems on the individual and on an abstract entity. The gene. This is demonstrable in a number of policy areas. If you look at the area of criminology, there has been a desire among criminologists for economic, not for scientific reasons, to do away with rehabilitation. Why put money into rehabilitation if it is "all in the genes?" This is the kind of argument that is going on in a number of policy areas: that if it is genetic, we do not need state resources to deal with it.

Karin Lohman, House Science Committee: As I am listening to this discussion I keep thinking that what we are talking about are issues that have been around for many years. When we are talking about racial profiling or access to health care, these are not new issues. Even in education, where you have the school systems and do we want them to take care of everything or are they just supposed to be educating and if so, who? So why do not we

segregate out, at least for simplicity for a while, and approach either the racial profiling or the access to health care. I know these have been hot issues but out of attacking one, you cannot really attack the other.
NELKIN: It is not that these are new issues. What is different is the use of a specific scientific approach as a justification. That is entirely new. Troy made reference to phrenology – at that time used for very similar purposes. A Canadian anthropologist has made an important point that science is a political resource.

DUSTER: Just a quick footnote: it was obvious I thought in my remarks about Lombroso that there is nothing new – at least in the quest. Italian criminology of the late 19th Century was all about trying to find out the cause of crime looking at the physical attributes of incarcerated individuals – usually at the structure of the forehead or other aspects of the physiognomy. But there is a difference in the two periods. Today, the imprimatur and authority of genetic science is so powerful that people are inclined to simply accept the definitive aspect of DNA analysis. We are unlikely to question research that characterizes genetic profiles (SNP profiles) of certain criminal populations – such as convicted sex offenders. The head of the national DNA criminal database has said that he "does not rule out the possibility" of future research on this database that could result in the DNA profiling of criminals. If we understand the nature of the underpinning of the science, we may have a different attitude towards such "findings."

In the last period, the calls for more and more people contributing their DNA have come from many, many different quarters. Again, if we go back only 15 years, the first DNA samples were taken from convicted sex offenders, and only in a few states. Now, every state not only collects and stores DNA samples for sex offenders, but most now add convicted murderers, violent offenders, and at least one-third of the states collect DNA samples on burglars. As of September 1999 Louisiana became the first state to collect DNA samples on all those merely arrested for a felony. Virginia joined Louisiana this year, as have two other states. Since the late 1980s we have almost a million DNA samples and state law in Virginia now requires that sex offenders are shown on a website.

What is new is the imprimatur of the authority of science and the notion that DNA is going to permit us to move towards a more error-proof criminal justice system. But this has double edges. The first edge is the Scheck-Neufeld Innocence Project. They have been able to use DNA testing to get several wrongfully convicted people off death row. That is new, dramatic, and an important development that we all can and should applaud. The flip side of that, which is also new, is that we should now be able to use these technologies to achieve what I referred to earlier as "cold hits" on the population. The "cold hits" are an interesting phenomenon, but as I said in my remarks, they depend upon who is in the database and who is being accessed in terms of placement procedures. That will be the natural segué from the health field, even though you said you want to separate the health and crime issues.

LOHMAN: Racial profiling from the actual number of people arrested and perceived as suspects. Those issues and the DNA database.

DUSTER: I actually would pull those two apart and then put them back together for a reason. I was making an argument that the health and medical issues around SNP profiling may be a legitimate first step in the hunt for disease-related genes. Let us take prostate cancer. The rate of prostate cancer among blacks is double that for whites. SNP profiling is used by the National Cancer Institute to take a clinical population of black males with prostate cancer to see if they can get a SNP profile of "their specific cancer." At one level that makes some sense, if we are going on a "gene hunt" for oncogenes.

The same technology of SNP profiling, however, is also going to be used by researchers in criminology, trying to figure out the DNA profiles of sex offenders – then violent criminals and then burglars. But unlike with the medical situation, in which the search for candidate genes is likely to continue, in the criminal justice context, the search is very much more likely to stop there – to stop only with the genetic profile. So that is the empirical connection. It is not that one cannot analytically pull apart the health research from the criminal justice research on DNA profiling. One can. But I think empirically we are going to see increasing pressures to use SNP profiling to

"better understand" criminality, and that is the danger. We know that this tool, as a device for looking at cancer of the prostate, is merely an early-stage hunting device. It is not an explanation for prostate cancer. With crime, the social and policy context is different, and will lead to some very different conclusions.

LOHMAN: I will ask another question. You perceive this as a problem and I actually agree with you. There is a potential problem that I think will be very complex – the linkage between SNPs and behavior and it is not going to be a single gene issue. It is the difference between qualitative and quantitative genetics. What sort of policy would you recommend policymakers set forth if we have to balance the potential health benefits versus the potential civil liberties violations?

DUSTER: First of all, in order to even get to the question about the policy issues, I think one has to be very mindful of the underpinnings and therefore the limits of the technology. So I think we need to understand SNP profiling as a very restricted tool. It is not a complicated tool. We are talking mainly about association and correlation here, not genetic causation. Only about ten per cent of the genome is in what are called coding regions (areas in which the genes instruct the proteins to produce certain outcomes), and all the rest of these SNPs are in non-coding regions (which used to be called "junk DNA"), which simply means we do not understand what function they might have. However, with a computer-assisted SNP profile we may glibly come to conclude – quite erroneously – that we have something more than a spurious correlation. When dealing with cancer, we know that all we have is a genetic profile, and not an understanding of the causes of that cancer.

To make things a bit more complicated, the Human Genome Project has now turned its attention to what is called a Haplotype Map. A haplotype is simply a collection of SNPs that occur in a region – that serves as a "marker" for some putative phenotype. In the health and medical context, this could be a disease, such as sickle cell anemia. A collection of SNPs around the gene causing the cells to sickle would be called a sickle cell haplotype. We should be clear that a haplotype is not an understanding of the function of the gene, and tells us nothing about the way in which the gene codes for a protein that produces the sickling, and so forth. Yet the haplotype mapping, the next stage of the Human Genome Project, is going to a remarkably interesting thing to watch – and we should do so with great care and scrutiny at the policy level. This is because haplotypes by their definition are associated with certain phenomenon and not others. There will be haplotypes for a certain kind of sickle cell found in West Africa, another for a kind of sickle cell found in central Greece, another for cystic fibrosis, and so forth. All will be different.

Look at the danger hovering over the haplotype discussion. The danger is once you leave the disease phenomenon, it will be easy and seductive to slip into the idea that there is a haplotype for a sex offender, or for a violent offender – without understanding gene function at all. Indeed, we have been witnessing some claims-making about a haplotype for a national or ethnic group. I did not talk about this in my remarks earlier. The Macrogen biotechnology company of Korea analyzed over 90,000 bacterial chromosomes of Koreans, and compared and contrasted these with the Celera map (of non-Koreans) and concluded that because of the difference, they had "come up with a genetic profile of an ethnic Korean." Now think of the policy implications of that. A haplotype of a specific ethnic group. We have Native Americans who are entitled to certain rights, including fishing in certain waters, owning and operating gambling casinos, etc. The question of what constitutes an "authentic" Native American therefore has interesting and consequential policy issues.

Howard Silver, Consortium of Social Science Associations: I am fascinated by your results, Susan, that people with first grade educations understand AIDS better than some other people in other places. What is going on in Guatemala that allows them to have all this knowledge with just a first grade education?

WELLER: It is not that they know it better than, but they know it as well as. First of all, I think you have to understand about AIDS and how people have learned about AIDS. This is not a traditional disease like the common cold that we have had with us for millennia and that has been well defined by the biomedical community. It is a new

disease. But there is also a way that we have reached people in most of the world now, and that is through the media. Through radio announcements, TV shows, even though these people do not have electricity, they have access to media. And the knowledge that they have and the beliefs they have formed about the disease have not come from experience, but what they have heard on the radio, and that is probably why knowledge about AIDS focuses more on transmission. I think the media message has been about how do you get it, what to do, what not to do. And I think that is the core of it as opposed to Puerto Ricans in Connecticut, many of whom have actually seen it.

I wanted to comment earlier and that was to change gears a little bit about how is it that behavior is being ignored in some of the genetic research and one of my colleagues gave a more macro view and I want to give a very micro view. I think some of this has to do with the culture of the way research is being conducted. Microbiologists simply do not know how to do clinical research. They are lab people. I have done research on HIV sexual transmission with condoms and you see incredible detail reported for laboratory tests. But when the key outcome variable in some of these studies is condom usage, but it is measured so naively that it is shocking, and it is unfortunate not to take advantage of social science expertise. There is a lot of skill involved in question asking and response recording. I think now is the time that we need inter-disciplinary research more than ever. Some genetic diseases are defined solely by social science methods. Take, for example, depression and schizophrenia. Although there is a hunt for the schizophrenic gene, the goal standard in validating findings is based on social science methods. These are paper and pencil tasks; interviews and questionnaires. It is not simply gene present or gene absent that determines whether the disease is present. Instead, the genetic data are compared to the interview/paper and pencil test results to validate genetic findings. We need a much better linkage between people working in the laboratory and those with expertise in the social sciences.

Jerry Sroufe, American Educational Research Association: I am wondering that the study of the transmission of knowledge about AIDS seems to be a fairly simple problem relative to the problem we have been discussing here in terms of knowledge and understanding. How and what would be your expectations about making the public aware of the complications of an issue that is so multi-faceted and which really requires a much more sophisticated understanding of science than just simply medical research. I have heard lots of terms today that I am not familiar with and I hope to learn about a cold hit. I assume that is an ice hockey comment.

WELLER: Unfortunately I do not have an answer for you but I think the problem is even bigger than you would expect. We have been doing some studies on screening for colorectal cancer and prostate cancer. We have explored patient perceptions of various screening modalities, not genetic screening, but early detection of cancer and options for treatment. The communication gap between the physician and the patient is enormous. What we have found in preliminary interviews is that a lot of people have no idea what prostate cancer is, what a prostate is, where it might be, or if only men have it. And even with simple concepts like what does "screening" mean, we find enormous gaps where people simply do not know what you are talking about. Patients understand use of a test that could detect cancer early, but they do not know what it means if you say a screening test. The communication gap is enormous.

DUSTER: About ten years ago the March of Dimes did a national survey on how much people know about genetics, what their attitudes are toward gene therapies and gene screening and testing. For the most part, the population was in favor of more genetic testing, more genetic screening, more genetic research and so forth. What is remarkable, however, is that the closer people get to the actual experience – that is, people who have been through the experience of gene testing screening – they have an almost completely different attitude towards these phenomenon. There is a large segment of the general public which has had no direct experience with medical or clinical genetics, but which is generally positive. The people who have strong views are those who have someone in their family with a gene disorder and then they often have a very different view about genetics and genetic

screening and testing and insurance and privacy than the general population. So, I think as we get more and more information in the next decade we will see a different attitude towards genetics than we have in recent years.

SHARPE: Since there are no more questions, please join me in giving our panel a round of applause. I want to thank you all for coming. There will be a transcript of the proceedings available in the near future.

SPEAKER'S BIOGRAPHIES / CONTACT INFO

Troy Duster is a Professor of Sociology at New York University, and Director of the American Cultures Center at the University of California at Berkeley, where he also has an appointment as Chancellor's Professor. He is a member of the American Association for the Advancement of Science Committee on Germ-Line Intervention, and chair of the Board of Directors of the Association of American Colleges and Universities. From 1996 - 1998, he served as chair of the joint NIH/DOE advisory committee on Ethical, Legal and Social Issues in the Human Genome Project *(The ELSI Working Group*). He is the former Director of the Institute for the Study of Social Change at the University of California, Berkeley. His books and monographs include *Cultural Perspectives on Biological Knowledge* (co-edited with Karen Garrett, 1984), and *Backdoor to Eugenics* (Routledge, 1990), a book on the social implications of the new technologies in molecular biology. His most recent publications on this topic are "The Sociology of Science and the Revolution in Molecular Biology," in J. Blau, ed., *Blackwell Companion to Sociology*," 2001, and "The Social Consequences of Genetic Disclosure," in Ronald Carson and Mark Rothstein, eds., *Culture and Biology*, Baltimore: Johns Hopkins University Press, 1999.

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Dorothy Nelkin holds a University Professorship at New York University teaching in the department of sociology and school of law. She is a member of the National Academy of Sciences Institute of Medicine. Her research examines science and law, science and society, and biotechnology regulation. She is the co-author of *The DNA Mystique: The Gene as Cultural Icon, and Body Bazaar: The Market for Human Tissue* in the Biotechnology Age. Her book chapters include "Genetic Predisposition and the Power of Prediction," in *Perspectives in Bioethics* "From Promise to Progress to Portents of Evil," in *Ethics and Values in Healthcare in the 21st Century*, and "Cancer Genetics ad Public Expectations" in *Inherited Susceptibility to Cancer*. Nelkin's recent articles include "DNA Identification and Surveillance Creep," in Sociology of Health and Illness and "Do the Dead Have Interests? Policy Issues for Research after Life," *American Journal of Law and Medicine* (both with Lori Andrews).

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Susan Weller is a Professor in Preventive Medicine and Community Health at the University of Texas Medical Branch, Galveston, Texas. She is currently working on a National Science Foundation funded research project examining the cultural beliefs and health status in Type 2 diabetics. Weller's previous research include an examination of "The Effectiveness of Condoms in Reducing Heterosexually Transmitted HIV," "Intercultural Variation in Beliefs" (funded by NSF), "Couples' Preference for Prostate Cancer Screening," funded by the National Institutes of Health. Weller's professional activities include serving on the

Board of Advisors, *Encyclopedia of Medical Anthropology*, the Editorial Board, *Field Methods*, and the Executive Board, Society for Medical Anthropology. She is a member of the American Anthropological Association, the American Statistical Association, American Public Health Association, the American Ambulatory Pediatric Association, and the Society for Applied Anthropology. She received her Ph.D. from the University of California, Irvine.

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Pictured from left to right: Susan Weller, Dorothy Nelkin, Angela Sharpe, Troy Duster

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