Policy Perspectives from Members of the Bioethics Community
Troy Duster, Ph.D.

DR. WILLARD: Our final speaker for the day is Troy Duster. Dr. Duster is Professor of Sociology at NYU and also holds a position of Chancellor's Professor at the University of California at Berkeley.

Dr. Duster, welcome. Thank you for being here.

DR. DUSTER: Well, first of all, some truth in advertising. I do have drinks with bioethicists, and I've been on committees with them, but I'm not a bioethicist. I'm a sociologist, and that will become clear in my remarks. I sat with three years on the ELSI working group, and just to give you an example of the kinds of issues which occur and recur, I would say that over those three years the most contentious topic that we dealt with was access to storing tissue samples. We had disagreements about many issues, but we often came to some kind of grudging consensus. On access to stored samples, we had no capacity to come to consensus.

Now, sociologically, I put that other hat on right away. What I was seeing was that interest groups, people in the biological or molecular fields or pharmaceuticals, anthropologists, had different angles of vision on this topic about access to stored samples. Of course, the bioethicists took what would be called the extreme position, no access unless there's consent before. The people in the research community thought this was kind of crazy because we're talking about delivering health to people. So how could you be against looking at a data set when if you really examined it with some care you could actually bring health to people? That's by way of prologue.

The prologue is that I'm a sociologist by training. I'm not a bioethicist. What I'm going to do is to step back from the project and make some rather broad statements, and then become more specific in the short time I have. I can collapse this presentation or expand it based upon the time allotted. I think I'll collapse it.

I thought it useful to think about this kind of project using a metaphor of the Chinese game of go. At the very beginning of the game, an infinite number of possible moves. But when you make the first two or three moves in the game, it limits almost dramatically what's possible. The same is true for a large research project. When you first start off, you've got a whole field of possible categories of inquiry, but when you begin to use in that first cut what the categories are, like in the game of go, you limit what's possible from thereon.

Now, let me start with a question that was asked of me, what might be one of the major concerns. Let's take the topic of does the research represent the population. Depending upon how a society is organized, the very categories of who is represented is vital to stage 1 of the study. Let's take a case where you have a society that's divided into Hindus, Moslems and Christians. Those are the major dividing lines between the categories of people in terms of access to resources, who has power, and so on.

Well, in that situation you would say we have to use that as the taxonomic system when we're talking about representation. Well, let's be specific. Let's go to India. Hindus have the most power there. There are Moslems and there are Christians. So one looks at the population and one would raise the question, what would be representation of this huge amount of Hindus that makes the most sense? Caste? In 1949, the caste system officially ended, but for the last 50 years, those of us who know a little bit about India know that it has residuals. The caste system isn't over.

So let's say one was going to do a large population study of India, and you wanted to talk about representativeness of the population. Would you use Brahman, Chitra, Dalit? Would you use those categories? And if you did, is there not some danger that you'd find allelic frequencies in those categories which coincided with those caste system categories?

Whoa! Now the question comes up right away, is the research reifying the taxonomic system that you thought you destroyed in 1949? People will raise the question, are you going to use race, coming back home to the topic here for a moment, as a taxonomic system when, in fact, we know race as a category has all kinds of fluidity biologically, socially, anthropologically, politically and culturally? We know that. So once you use the notion of race and you're going to use genes, like the Dalits and Brahmans of India, are we not as researchers in danger of providing a kind of reification of that taxonomic system? So that's the question, that's the concern.

Surely, after 3,000 years of a caste system, where you only can marry inside of a particular caste, you'd find allelic frequency variations which were pretty common in certain groups and not in others. But when you interpreted those results, would you conclude that this was about genetics or rules of monogamy, heterogamy, endogamy, anthropological rules? Because the rules of engagement around sex in India are not so much about biology but about those cultural rules. The cultural rules produce allelic frequencies in castes A, B and C which turn out to maybe have outcomes for health.

I'm going back and forth between India and our own culture for obvious reasons, because we are clear when it comes to India that this might be problematic. We get a little bit foggy in our own country about this taxonomic system. I'll say in a few moments how this might be addressed. The relevance for the U.S. will become obvious.

What does it mean to have a population study as representative in the U.S.? We obviously want whites and blacks, we want Asians. We care less about Christians, Jews, Moslems and Hindus. Why? Because it's not part of the stratification system in our own conception of what's deeply embedded in the structure. That's not about biology. That's about social categories. We can say let's have a study which represents Christians, Moslems, Jews; you'd be laughed off the block here, but not in other places.

One half of all cancers occur among people living in industrialized parts of the world, one half of all cancers. This group constitutes one-fifth of the world's population. The World Health Organization collected data on cancer rates from 70 countries, and here's a direct quote from the WHO's study: "Eighty percent of all cancers are attributable to environmental influences." So step back for a moment and look at those two figures. Half of all cancers that we know about are occurring in one-fifth of the world's population, many in the industrialized world.

Now, migrant studies are among the most powerfully persuasive ones in sharpening the environmental sources of high incidences of cancer. Jewish women who migrate from North Africa, where breast cancer is rare, to Israel, a nation with a high incidence, (inaudible) that breast cancer risk is half of the Israeli counterparts. Within 30 years, African-born and Israeli-born Jews show identical cancer rates. One of the most compelling environmental studies of cancer ever conducted, researchers found an association which was significant between the use of cultural chemicals and cancer mortality in 1,497 rural communities.

A study that represents the population. Could we not have a study which represents those who live around toxic waste dumps and those who don't? A study that looks at those who are handling chemicals and those who don't? That is, it may not be that race or other kinds of social

taxonomic differentiations is there. Maybe what these data are showing is that the representativeness of the population that's relevant to a health study on cancer could be what I think someone said in the earlier session, maybe has nothing to do with race, unless race puts you around a toxic waste dump.

The work of Julie Shay in New York City, her doctoral thesis about three years ago, what she found was that there were four important waste sites, and it turns out that the African American population was living much more around those waste sites than were upper middle class white people. No big surprise, but it does have some bearing on how you would design a study.

Now, if you're talking about genes and environment, that's the way this is being framed, it sounds kind of good. It sounds like we're going to look at genes and environment. But this table is not set evenly. The ones doing the research on the genetics of these kinds of problems, whether it's hypertension or cancer or you name it, it tends to be the notion that they're doing the really hard science. They're doing the close-up empirical work, and those doing work around toxic waste dumps, that's kind of epidemiological, soft, humanistic, not very focused, not hard data. And yet the data that would seem to me to be most compelling are the ones that I just gave you.

Where is the cancer rate in this country? It's around these various sites. So my concern, if you haven't quite figured this out, is that the framing of the study as genes and environment already is assuming that there's a kind of interaction here that's more or less equal. In fact, and I think empirically, one can say we've got good data that the environment is going to play a dominant role in many of these kinds of diseases, that genes will play some role, but that when we put it together it will sound like the real imprimatur of science is on the genetic side. What's the bearing of this? Well, I'll give you an example. I told you I could expand or collapse. I'm going to collapse here in a few minutes and open this up for a conversation.

The example is the one that most of you are already familiar with, the fact that we now have a particular market for a hypertension drug for African Americans. I'm not going to belabor the point, but I'm going to make the point in the following way. It's not so much about genes; it's about how one thinks about the problem.

If you find that a population of African Americans, or any ethnic group, has a higher rate of something, and then you find that there's some kind of a shift or an imputation of a shift in the bodies of those people, you'll say, well, it must be about their ethnic or racial category. Well, the work of some epidemiologists suggests that it does depend on whether or not you can do migrant studies or cross-cultural studies. So hypertension in the black community is high in this country, but if you go across and look at the work of Richard Cooper looking at eight different countries, three different continents, comparing hypertension among blacks and whites in these different countries, he finds that the differences either go away, certainly not clearly that it's racial.

In this country, staying only inside our own borders, looking at a national study, seeing high rates of hypertension among black people, we might say allelic frequencies seem to show that this is a more common phenomenon over here, and we might therefore make this huge mistake inside our own boundaries. If we look, however, at Brazil, at sub-Saharan Africa, at the Caribbean, as Cooper has done, and we show that these differences begin to shift around, then the whole enterprise looks very, very different.

Prostate cancer. I'll end with that. The black prostate cancer rate in this country is double that of the white prostate cancer rate. Let's say you do a national study and you find this, you find more national data indicating that it's the case, and you might find using computer technology that you

would see allelic frequencies in the black population which were different from the white population. You might find that. It wouldn't surprise me at all.

However, to leap to the conclusion that the prostate cancer rates are a function of these differences in the genetic structure is a huge leap unless you have functional genomics. Well, we're some way away from that. So the question is going to be what do you make of these data? It goes back to the game of go. If at stage 1 you've decided that the taxonomic system you're going to deploy is using race, then how these data are reported out that you just heard becomes vital. As a social scientist, what deeply concerns me is that the table is set so that the genetic interpretation has the imprimatur of more power analytically when, in fact, the data set might indicate that if you went cross-cultural, cross-national, migrant studies, you'd have a different conclusion.

So my advice is expand this always to talk about migrant studies and cross-cultural, and include that in any kind of attempt to talk about a national study. Otherwise you've set into motion at stage 1 in the game of go, and you'll see where you'll wind up, with a reification of race.

Thank you.

DR. WILLARD: Thank you, Dr. Duster, and thanks to all three of you.