



## **Focus Group Phase Report**

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## 1. Introduction

This paper reports on focus group interviews used to gain an understanding of issues of concern related to genetic research and its applications in communities of color. Focus groups were conducted with members of the African American and Latino communities in several areas of Michigan. Future groups are also planned for Tuskegee, Alabama. The results of the focus groups are intended to convey public opinion about genetics and uses of genetic technology from the perspective and experience of the participants. Their responses will be utilized to develop a “menu” of issues to be discussed in greater detail in community dialogue sessions during the next phase of this research.

Teams of three individuals, a facilitator, a genetics educator, and an observer, were present at each group. The facilitator began each session with a brief explanation of the human genome project and then asked the group a question about concerns they might have regarding genetics and genetic research. The investigators charged with evaluation of the project requested that this first question be asked to gauge the groups’ familiarity with the subject matter prior to hearing the presentation by the genetics educator. This opening question and answer session was followed by a 20-30 minute presentation by the genetics educator about basic genetic concepts and current applications of genetic technology. Slides were used extensively during this presentation in an effort to ensure that the information presented was understandable. The participants were encouraged to ask any questions they may have had regarding the information presented. After all questions were answered the group discussion continued. Throughout the discussion the observer made note of key issues mentioned by group participants. These points were presented to the group at the end of the session in summary form and the individual participants were asked to order the items by importance.

The teams for the Latino groups were bilingual. One of the groups was conducted in a mix of English and Spanish. The African American groups were run by African Americans.

Seven focus groups were conducted, but due to human and mechanical error, actual transcripts exist for only five of the groups. This paper will only report on those five groups -- two African American groups and three Latino groups.

The participants for the focus groups were recruited by community organizations. The project staff worked closely with the community groups to set criteria for the composition of the groups. Attempts were made to vary the groups in terms of age, gender, education and socioeconomic status. This was done to insure the inclusion of a mix of experiences and viewpoints. There were at least 10 participants in each group. Ages ranged from 20 to 75 years of age; there were 39 females and 14 males; and 25 were college graduates.

The following tables present gender and age data for the five groups.

### Latino Groups:

Gender			
Location	Male	Female	Total
Saginaw	2	10	12
Detroit	2	9	11
Grand Rapids	2	8	10
Total	6	27	33

Age							
Location	20 or less	21-30	31-40	41-50	51-60	61 or older	Total
Saginaw	0	2	2	1	3	4	12
Detroit	1	7	2	0	1	0	11
Grand Rapids	0	5	2	3	0	0	10
Total	1	14	6	3	4	4	33

### African American Groups:

Gender			
Location	Male	Female	Total
Ann Arbor	3	7	10
Lansing	5	5	10
Total	8	12	20

Age							
Location	20 or less	21-30	31-40	41-50	51-60	61 or older	Total
Ann Arbor	0	0	0	3	4	3	10
Lansing	1	1	2	2	1	3	10
Total	1	1	2	5	5	6	20

Other demographic data (education, income) is presented in an appendix to this report.

The next two sections of this report present the main points made by the participants. Each ethnic group, African American and Latino, is considered separately. Three points should be noted:

- Within each group, the discussion is partitioned into two parts: before the educational piece and after the educational piece. This is done in an attempt to detect possible differences in attitudes and knowledge before and after the educational piece.
- In the body of this report we attempt to let the focus groups' participants speak for themselves. Quotes are used liberally, and text is used primarily to connect themes raised by the participants.
- The final section (Section 4) attempts to summarize the groups' opinions, and to compare and contrast opinions between the two ethnic groups.

## 2. African American Focus Groups

### Before the educational piece:

Each person in the group was asked if they would voice one concern about genetics and genetics research. The primary issues that were raised at this point involved the use of genetic testing for health insurance and employment, lack of trust in government (including hidden social and political agendas), privacy, information control and access, and cloning.

### *Genetic testing and profiling for health insurance and employment*

A concern, voiced often throughout the focus groups, is that genetic testing will be used to determine access to health insurance and screen applicants for employment.

*I am most concerned because I have an illness that has a genetic basis and I think that genetics is now being used to redline for health insurance, health coverage and mental health coverage.*

*I have an immediate concern of perhaps profiling [by] employers, public employers and to discriminate against people who have certain genes for insurance purposes. I can see public employers refusing to hire people if they felt the insurance obligation would be greater than [for] some other person.*

*Most of us have a hard time getting insurance anyway, but it would just be one more thing that insurance companies can use to deny us coverage.*

### *Lack of trust in government and institutions*

The members of the focus groups seemed acutely aware of the Tuskegee experiment, and concerns were raised about the motivation of government and researchers. One participant even raised the possibility of genocide.

*I'm not trusting anything the government does that's supposed to be helpful to black folks. I just don't trust anything they do, and I would advise anybody that takes any advice from me ... to not be involved [with] anything to do with the government until we know absolutely sure what they are going to do with it. I don't want to have any information in any data bank. I am just very distrustful. We need to remember what they did to our men in Tuskegee.... We've got to be really careful anytime Uncle Sam comes to black folk and says "Let me help you". You'd better watch your wallet and watch your hand and watch them.*

*My main concern is that when you get into something like this, there must be some kind of way that they, whoever they are, are trying to do away with a race of people – like black people.*

*I find myself a little distrustful because just the way things are and what I really think and what's your real purpose. ... [You] present one thing to me and then your underlying primary purpose is something else.*

## ***Privacy***

The issue of privacy (who has access to genetic information) is clearly closely related to the issues of the uses of such information, and who controls it.

*My concern is exactly what kind of studies they are doing, what effect it will have on my insurance coverage and my job – the information that is out there to the world and who has that control.*

*My concern with genetics is the profiling.... Who would have access to this information and what would be done with this information?*

## ***Cloning***

The views that were expressed at this point about cloning appear to stem from a lack of information and from ethical considerations.

*I have a concern with cloning. I know they cloned a sheep a few years back, but they didn't tell us what happened up to that point. So they were talking about doing that with human beings in the future. What's going to happen in between – to where we get to this end?*

*I have a concern with cloning because it is not ethical.*

## **After the educational piece:**

Following the educational piece, the groups raised and discussed a wide range of issues. These included the involvement of African Americans in policy decisions, education, access to information, genetic counseling, genetic screening, genetic engineering and gene therapy, cloning, and scientific research. This report discusses these now.

## ***The involvement of African Americans in the process***

The group members expressed strongly the opinion that African Americans should be involved in policy making, as well as active participants in genetics research. They also saw the focus groups as an effort to engage them in the process, and they voiced the opinion that genetics research needed to be discussed in their communities. Many expressed the view that African Americans need to be pro-active in supporting education, and in disseminating information in their communities.

*We need to become cautious enough to identify the concerns and problems so that we can address them ... and we ought to focus on what the benefits are and guard against the dangers. I don't know how to do that, but that's what we ought to be trying to do.*

*We as a people need to make sure that we have enough people who are going into science and research so we know what's going on.*

*What we have to do is to be involved in the education and the research and make sure that we are opening the pipeline and encouraging our young people. Not too many of our young people want to go into the research part of science – they all want to be MD's.*

*[We need people] of color in on the decision making who ... have a sense of community ... to look out for our people. And I see that as a primary focus of this. ... We have to make sure that we have people in all aspects of this who are community minded – people that make sure that we don't get taken advantage of and who are looking out for people, African American, Hispanic, Latino, in the community -- that we aren't taken advantage of again like we [were] in the Tuskegee syphilis study.*

*Let's support these Ph.D.'s who are ... minorities and encourage our children to grow up and make a difference in that area. Instead of just being in the background ... let's be an active part. Let's be these scientists, and let's make sure that if something good is going on, that I'm included, that my race is included.*

*I think, when I look around this room, we're all connected in some way or another, and my question is whether we're raising ... questions where we live – in organizations in the community? Is that not a way for us to do the things we need to do to encourage our children to go into the field, to encourage the professionals who are already going in the field, to make sure that we know who our policy makers are and what their views are on all these issues and to invite them into our groups, into our organizations, into our churches, into wherever we are, to make sure that we generate enough discussion in the African American community so it's in the light. So whatever happens is in the light and it's not [us going along trusting] that someone else is taking care of the problem. I think all of us can do something.*

*There is no difference with the genetics problems than with all the other problems that we have faced in this country and attitudes shaping in this country, and how we can affect them.*

### ***Distrust of government***

Distrust of the government was voiced on numerous occasions. The focus groups were keenly aware of previous experimentation on African Americans, and saw the possibility that this might continue. They were also suspicious of motives for keeping medical information.

*My concern again is trust. ... I am just very distrustful of the federal government when they say they are going to do anything that is positive for black folks. I mean, we've got to be really careful. I'm telling you, we're the low man on the totem pole, and if they're going to experiment on anybody it's going to be with us. We've got to be really careful.*

*There is a benefit for cystic fibrosis. Sickle cell, cancer – I agree with that 100 percent – but we've got to be wary as to who's going to be the guinea pigs on this deal and it's probably going to be us. ... And that's what we've got to be wary of, and not just ... look at the benefits, because historically, they've proven who's going to be the guinea pigs. And there is no low man under us.*

*And now they're throwing a bone at us ... we'll throw in sickle cell, you know, one of your main diseases, genetic diseases, now you cannot be as afraid as you were before,*

*because syphilis was something different. And now sickle cell is a genetic disease and OK, we'll cure this for you. But we may give you ten other things that you need to worry about. And that's what we have to be leery of ...*

*The federal government doesn't have any real time for African American people. It's like that whole "Big Daddy" thing, and I am always suspicious when people say: "I am keeping a record of this, but I am going to keep, just keep, it. I don't know what I'm going to do with it."*

## **Cloning**

The focus groups' discussions about cloning raised a number of concerns. One was that this would interfere with natural selection and evolution. This concern was also raised in connection with genetic engineering.

*I know that a lot of times through evolution, a lot of our birth defects are things we don't need in our body ... it's lost or clarified or cleaned up. And I'm concerned that everything will be passed on, so evolution will not continue, evolution will be basically stopped, with the cloning of genes. We will not evolve as a being.*

*What happens to the mishaps in ... the cloning? And we ... bring this into the human race and what happens if we let that being grow up and there's a screw-up...? ... And this person is reproducing with others in society – that's a huge concern. ... What happens when this comes into the human race? What does it do to our genes then?*

*Once you begin to use genetics to make selections regarding people ... you can mate the population by selective breeding. We've been bred a long time, but we are getting rid of the natural selection and we don't know how these new things are going to do.*

There was also concern that, although there might be benefits to cloning, there were also dangers.

*I understand that ... you could take the genes and maybe someone who needs a match for bone marrow can get a match. I understand that. But ... you could be cloning the next Ted Kazinski, the next Jeffrey Dalmer, or someone of that nature, and ... I don't want to bring those types of people into our society.*

Concerns about, and objections to, cloning that stemmed from ethical, moral and religious considerations were also raised.

*I'm very concerned [about] the use of cloning for spare parts. ... I think that opens up a whole realm of ethical, moral issues that I don't think we have begun to deal with. ... [Who] would allow their child to die and turn down clones for spare parts to fix them up? And if you would do that with your own child and if you sat there you have the power and the authority to do that with a host of people and you might be able to wipe out certain illnesses, what might happen?*

*Morally I don't think it's ethical. I believe my faith teaches me that is not what should happen: cloning, period. That is an aspect that goes against my religious beliefs. ... I just think that someone is trying to play God when you go into the cloning aspect. And I don't think that ought to happen, that we are allowed to play God. ... [When] you start messing with the human being, that really stretches it on a spiritual and moral level.*

Ethical concerns about the rights of clones were expressed.

*[What] are the rights of a cloned individual? If we clone an individual today, do we have the right to take that person's heart, that person's lungs? What rights do they have? Who gets those parts? Is it the person who has been cloned – do they have a say in that? Is it to the highest bidder? And then, if you are that cloned individual, are you protected by the Constitution? What kinds of rights do you have for instance?*

The opinion that cloning might lead to further breakdown of the family structure was also voiced, along with additional concerns about growing spare body parts and even slavery:

*I think the big issue is that cloning breaks down family structure -- the issue [that] the person can be cloned from your brother or father or whoever. I think there are issues of family units that are developed – one person [cloning] themselves is [an] extremely narcissistic issue. ... It leaves the door open for parts manufacturing. ... If cloning had existed 200 years ago, we would really be in trouble. I wouldn't put it past anybody to begin to create people for their own purpose.*

*We already have people that are having babies to extract marrow. ... They love the kid but ... the first cause in having the kid was bone marrow. ... You get such a spiritual disconnect of humanity.*

Another issue that was raised was the feeling that the use of cloning might further disadvantage and polarize African Americans:

*[Cloning] is [not] necessarily immoral or unethical because .. there [are] a lot of ... procedures that are used today that in the past probably were considered immoral or unethical but are accepted today. I think there obviously have to be some major concerns about cloning of individuals. ... It's a frightening thing and that's why I think information is key because we could easily tip over into something that is very dangerous – I think particularly dangerous to people who are not normally in the power structure or control structure, people of color basically. I think there's already institutionalized discrimination and this has the potential to super-solidify that as a society.*

The cloning of animals for food was viewed with some suspicion by one participant:

*They have [been] cloning chickens. What are they going to do eventually with these chickens when they are done? Are they going to kill them and put them into the market for human consumption without knowing what dangers these chickens could do when they get into your body? And the effects of those chickens may be far reaching in the long range and we may not know today.*

A contrasting view was expressed by another participant:

*I think the food thing could be beneficial... -- in terms of experimentation to determine whether or not you can have stable food supplies or you don't have to deal with famine or droughts and could ensure the world's population or supply food without starving to death. [If] that could be done feasibly or economically, I think that would be a real benefit.*

### ***Genetic testing, profiling for health insurance and employment, and privacy***

As they did before the educational piece, the groups expressed concern about how genetic information might be used by insurance companies and employers. Much of the concern appears to stem from the government's willingness to share and sell other types of information. A major issue for the participants concerned the question of who has access to genetic information, and the purposes for which such information might be used.

*I think the person who should have access to my information is the individual who I say can have access to it, period. It's mine.*

*If my mama had [a disease], then I might have [it], or pass it down to my children, and [the insurance companies could] say: "Since we're in the business to make money it's best that [we] not insure you." If I could be assured that this kind of information would be protected, I wouldn't be so leery. ... They are already using information that is supposed to be personal or private. ... They're selling driver's license information to prospective insurance companies, they're selling it to people who send you junk mail. ... Why do we think they're going to be ethical and not sell the same [genetic] data to insurance folks to exclude probably us – because it would be a lot cheaper to exclude all the black folks who might have sickle cell anemia. I'm just very concerned.*

*Once they have your genetic profile, [you could be] denied a job, based on the fact that you are a carrier of a certain genetic disease.*

*I want to give an example ... [It] was a young woman whose mother and grandmother and sister all had breast cancer, and the recommendation was made that before she developed breast cancer, she should just have a double mastectomy and get it over with. And she decided that she would ... have some testing done to see if she had genes that would suggest that she had breast cancer. And of course ... the insurance company is not going to pay for that – and that's one of the issues that might be involved. So she decided to go on and pay for it herself.*

*As someone who does have a genetic [disease in the family] ... if I were to be tested I would probably have [a] colon cancer gene. But the real issue here is – who has access to that information...? ... [If] I change jobs I will be going to another group health insurance plan because no one else is going to cover me. And who has access to that? I mean, does any potential employer who I may want to work for get the information that this person may have this disease and [can then decide] whether or not [they] want to spend the money because [I] may be a medical risk? So, who has the right to have access to that information for genetic testing? And that's a real concern because right now I don't think there are any limitations. ... On the one hand I would like to know some of the genetic answers. I would like to know whether or not I am passing [this gene] on to my child. On the other hand, you can't afford to know because if you do know you are totally locked in. Can't get life insurance, can't get health insurance – and that's ... the way it is now. I have no idea how much more serious it could get.*

There was also a view expressed that privacy might have to be compromised for the good of society:

*I think there's public health concerns, ... where your individual privacy has to be compromised for the greater good. If there wasn't the type of testing that's going on at birth, you could have wide outbreaks of [the] diseases that are being monitored. And so, although I understand and I agree with individual privacy, what that could cause in terms of public health issues is too great. What happens if that line is crossed and it's misused...? Now how to monitor that I guess is still the question – so that it can be used for your good and not for your detriment.*

## **Gene Therapy**

The groups expressed positive, yet guarded, optimism about the promise of gene therapy. For example:

*I think the general idea is to help and I guess sometimes things don't always go perfectly. And I know that sometimes we don't quite trust our scientists and some people, but I wouldn't want to give it all up because I'm not sure. Because there's a lot of good things that we can benefit from, ... medically. Maybe we can select the genes out of that person's genome and eliminate the sickle cell trait. And when you eliminate the trait, maybe you eliminate the disease...*

Ethical concerns were also raised, similar to those raised in connection with the use of clones for parts:

*[There's] an ethical concern utilizing fetal tissue to implant in Parkinson's patients to make them better. ... [The] caution I would take is when we start using other humans and parts to implant new things for science. ... [When] you start using anybody else, then it's not [OK].*

## **Genetic counseling**

The groups tended to see genetic counseling as a positive development, allowing people access to information and being able to make informed decisions and allocate resources accordingly.

*For someone anticipating marriage and having children, I think genetic counseling would probably be a good idea. I don't know if it would change their mind or not... This is what God intended it to be and we'll just do the genetic testing ... so that when that child is born we'll have all of the resources available to take care of that particular disease. But I can see where that may have, can have, implications when you are anticipating and planning ... a family.*

*[With] counseling, it gives you the foresight to see if [certain] things are going to happen and you can decide if you want to deal with it, prepare for it – monetarily, because not all insurance ... is going to provide special education and even nurses for a child that's born with defects.*

*I think of the genetic tests that can be helpful for planning for individuals having in mind to produce as a couple, ... and want to make a decision as to [whether to] have kids. ... It can be helpful in planning about what to do.*

The optimism about counseling was counterbalanced by those who wondered if too much information was necessarily a good thing. How would it help to know that one had an incurable disease? How much should one be concerned with societal views?

*I saw [a] film and ... this question had come up, about genetic testing. I think it was Huntington's Chorea, I'm not sure which disease it was, but ... you just start to fall apart around 40. It was something that has a genetic link... Would you want to know? ... I don't know that I'd want to know that. You have no control over it. There's nothing you can do to improve your chances. It's a 90 to 1 percent chance that it's going to happen to you at 40, 50, 60, or 80. But more than likely it's going to happen. But would you want to know?*

*[Will you be] perceived as ... selfish by society if you don't marry a person because they have a certain genetic trait – if you know in the future that your child is going to have sickle cell if both of you are carrying the trait? Then yourself, how are you perceived?*

*Sometimes what you don't know won't hurt you, depending on who you are and what kind of knowledge you want to have. I myself would like to know as much about myself as possible so that I don't have to worry about it – find out about it and be done with it and deal with it. Other people are afraid to deal with it, a lot of information.*

### ***Access to the benefits of genetic technology, and staying focused on relevant diseases***

Concerns were expressed about access to genetic technology. An example:

*I'm concerned that as African Americans there are a number of our people who still don't have the means, economically, to ... benefit from the results of ... the genetic research. [That's] apart from whether the research itself is good or bad or leading to some horrible consequences. If we come up with good uses for genetic research, will it be accessible for all levels of our people?*

Members of the groups voiced the opinion that research should be focused on diseases particularly relevant to the African American community, and that resources should be made available to support this research.

*I want to make sure that through this whole process the things that we have clearly identified, like sickle cell anemia and HIV, that private sources and government continue to support, or increase the support on, the research for cures. I want to see ... Howard, Tuskegee and those places continue to get support because I think we are going to solve three or four of those things we've identified, just as long as we don't let them drop off the screen for other things.*

*I'm very concerned about ... financing if there's certain diseases, like cystic fibrosis, that is not one that is primarily held by African Americans – what funding follows that one as opposed to sickle cell. Those kinds of decisions – if you're holding the purse and there's a disease that influences you more than others, the money might tend to flow that way.*

### ***Research and science***

Skepticism was expressed about the nature and direction of scientific research (“science for science’s sake”) – and the resulting tension with societal and spiritual values.

*There is a sense of helplessness with science – the more science, the more you move down the path. All you can do is wait and see. I don't know if that's a healthy mindset [for] society to have, that people can go forward just because they can. ... Somewhere society is going to put its foot down. I think we need to grab hold of some moral values before we just keep pushing [for] more and more that we think is out there.*

*There are pros and cons to everything, and we have to just try to be guided and not blindly led by science.*

Although misguided, concern was also expressed about the nature of scientific experiments in genetics research:

*All of us know that for good research projects we need a control group and an experimental group. Unfortunately you cannot have a control group and an experimental group in genetics.*

### 3. Latino Focus Groups

#### Before the educational piece:

The initial question asked in each group was more focused than in the African American groups. It asked each person to express any concerns they had about privacy issues, and access and use of genetic information.

In some members of the groups, there appeared to be a lack of understanding of the meaning of the word “genetics”. It is not clear if this was due to a language barrier, or to genuine unawareness. In addition, there appeared to be some reticence to voicing an opinion, and this may be cultural in origin. When asked if they had any concerns about genetics, two people replied “No”; and two others responded:

*[I] don't understand the word genetics.*

*I don't have an opinion [on] it.*

Some members of the groups voiced opinions about issues such as education, the benefits of genetics research, fears of discrimination by employers and insurers, and the role of institutions.

In contrast to the African American groups, some optimism about the future was expressed:

*I believe that genetic research will turn out very interesting. I believe that it is time to better the human race in many aspects.*

*I hear of the benefits when a gene from a mom is presented to a baby and it is possible to intervene for health reasons. I believe it is a benefit. I would also like to say that if it is possible to offer this... to everyone in general, it would be a benefit.*

#### ***The need for education, and access to information and benefits of genetics research***

Members of the groups expressed a need for more education and information about genetics research, in addition to concerns that access to the benefits be widely available. A concern for community was also voiced

*Because of ignorance, one has a false idea of what is being done, or of what is going to be done. Thus, what worries me most is ... not having the necessary information in order to know which are the scientific projects that they are carrying out and what are they going to do with those projects.*

*I am very interested in this topic personally because in my family there is a genetic problem. It is very important to be more knowledgeable. ... They are genetic problems that can be inherited, and this is a very important topic – to have more knowledge and know and understand more of life and the problems that affect us.*

*I would like to educate myself more ... perhaps to a not professional level, to inform the community due to many bad, mistaken ideas. It also interests me a lot – who has access*

*to the genetic information and what they can do with it, because it can be done in a mistaken form.*

*I guess my major concern is just that whatever benefits that we can get from genetic research need to be available to everybody in society. That's my concern – that it might not be available to everybody.*

*When I think about genetics, what worries me most is not only how to use the information, but that the benefits of genetics will be applied to all of society, not just certain people...*

*I am a community worker and I would like to know more of the facts and to distribute true facts in the community. I give myself credit for being a [contact] point between the community and the services...*

### ***Genetic testing and profiling for health insurance and employment***

Concerns were expressed that genetic screening would affect insurance and employment.

*What would worry me is that, based on the results of the genetics tests, a person could be discriminated against, be it in work or when one seeks medical insurance.*

*What worries me is that there may be an individual who is susceptible to a disease or that could acquire a disease and they encounter discrimination at the time of employment or looking for medical insurance.*

*I read about the insurers [who] won't insure you if they know that you have a type of cancer or things like that.*

*Either you won't get insurance or the insurance is going to drop you ... if they know.*

### ***Lack of trust in institutions***

Unlike the African American groups, not many comments were made at this stage which could be interpreted specifically as a lack of trust in government. The following is an exception, and perhaps this has more to do with a concern that the government may not be providing adequate oversight:

*The concern I have is that many of the programs that they give funding to, they do studies that try to use the people like guinea pigs, and don't give them services that they deserve, that they need, and on the contrary, they use them like a statistic.*

### After the educational piece:

Following the educational piece, the three focus groups raised a number of issues. These included: cloning, privacy and access to information, access to genetic technology, genetic screening, government, and scientific research. We now discuss these.

#### *Cloning*

Views were expressed that the government will ignore the opinions of Latinos, and that adequate oversight will not be available to prevent human cloning.

*[If] they get all this information about ... cloning, ... then all of a sudden the government is going to go ahead and do it, regardless of how we feel about it.*

*Yeah, the government's saying that [human cloning is not allowed], but ... what if somebody's doing that on the sly somewhere just to see if that can be done.*

*They'll tell you: "Oh, we're going to do this for medical purposes". "Oh great, we'll participate." But then they turn around and use it for something else, without you knowing.*

The motives of researchers involved in cloning were also called into question:

*[They'll clone] because they'll want all one kind of people.*

*Yeah, they'll say we can clone perfect people, perfect kids, that won't never ... do violence or anything like that.*

*They're probably going to want to clone perfect people, so what's going to happen to all of us that are not perfect? What happens? Some people have a lot of diseases. ... Or maybe they'll try to make us all perfect.*

One group member expressed an ethical objection to cloning:

*There is a difference between cloning of animals and of humans. With animal cloning, I believe that it doesn't concern me. Perhaps it will affect me in the future. But I don't believe in human cloning. I don't believe in that.*

Some skepticism was expressed concerning the possible benefits to the world's food supply through the use of cloning and genetic engineering.

*I believe that if the governments that have a lot of money will subsidize that people in order to clone animals that have a lot of meat, or that have a lot of milk, much of the poverty in the world would end. But that is a dream, it won't happen.*

*[Let's] suppose that 500 more cows can be produced, or let's suppose that in Mexico a more resistant corn is produced which allows a greater production of corn, etc. ... [It's] of little importance when the system continues as it does. To what am I referring? This is a system that produces poor people, independently of knowledge that one has this system [which] produces poor people. It needs poor people, it needs*

*manual labor, it needs people ... to move the machines. I mean, that's not going to change thanks to genetics. It's putting too much hope in genetics. That is a social question, a political question.*

### ***Genetic testing, profiling for health insurance and employment, and privacy***

Concerns about the privacy of genetic information were expressed.

*You know how many times they say that no one is going to know, but suddenly, like your address they send you papers from wherever – they already have your name. Who is going to have this information? And how can it affect us or our children? ... That which they say is private – no one is going to know – and ten people already know.*

*Here the government has this sample. Are you comfortable knowing that they have this sample? What are they doing about it? Who else knows about it.*

*I think we should give consent ... That we have that right – to say, OK, I consent for you to use [my genetic information in] the study...*

The potential that genetic screening might affect insurance and jobs was clearly a concern:

*[They could use genetic screening to] not give you a life insurance policy or whatever, you know.*

*[How] in a capitalist society like this, ... how are they going to begin to perhaps controlling that information, and without us knowing, [there's] going to be discrimination, ... for the types of work, for a certain type of person, for who there are certain characteristics...? This I believe, being realistic – there will not be much control.*

*I believe that all those benefits [of genetic research] are going to be exploited over insurance.*

*Perhaps it can be that the insurance won't insure you because you have a huge problem and they already know that there is a loss with you.*

*Simply as Latinos ... we have susceptibility to diabetes. Almost all of us have the genetics for diabetes. Beforehand they already know that, being that race, they already have disposition to certain sufferings and they can reject you automatically, your employer, your health insurance.*

### ***Access to the benefits of genetic technology***

The groups expressed concern that Latinos, primarily because of economic status and through lack of information, might not have access to benefits arising from genetic research.

*[If] it's something that can be done, who's going to be able to take advantage of [it]? The poor? The rich? I mean, if I say I want a perfect body, then if I don't have the money, am I going to have the same opportunities?*

*...genetics can bring, and is in fact already bringing, a level of wellness ... in the question of health. ... However, we also have to ask ourselves: "For whom does it bring this level of wellness?" Who can accede to it and who cannot accede to it? ... [Science] is always directed at a group of people...*

*I believe that the greatest risk in this case for Latinos is that there isn't economic access, nor political. This is the limitation. [It's] going to be an elite group that will control the benefits, and ... it's going to have a high cost. And the Latino people included are going to be completely unaware... And of course they will not have the economic ability.*

*The people need more information about [genetics research] – what it could do and what it doesn't.*

### ***Genetic screening, genetic counseling, and gene therapy***

Gene therapy was viewed with some suspicion, for both ethical and social reasons:

*It just sounds scary, trying to change something that is already human being. Why go back and change it?*

*Perhaps also there is the risk of manipulating the gene that has the information of aging and that the people would be eternally young. That would be a grave problem from the point of view that the people won't die.*

Genetic screening and counseling were viewed more positively, but an opinion was expressed that the latter might make little difference:

*If one could have genetic information earlier, many people would think about having kids. If I know that I have in my genetic information, but if I have it and they tell me I have the probability of having a retarded kid, then what do I do? Automatically I don't want to have kids.*

*The women we see here pregnant [are offered] certain tests, among them one that detects genetic abnormalities. And the question always is: would you change your decision to have your child if he had an abnormality like Downs? And they always answer: No, I would have my child.*

### ***Distrust of government***

Two people in the groups took a skeptical view of the government's motives in collecting genetic information.

*The FBI is going to make this federal [gene] bank, ... so they have the archived fingerprints, the genes. The question is: Who is going to be the police of the police? In this case, who is going to control the FBI? I mean, who is going to control it? ... [In] the United States there is an enormous tradition of secret projects at all levels, at all*

*levels. The United States has a tradition of not saying to its people what they are doing.*

*[The USA] is characterized by secrets, and they are going to have [genetic information] without giving it to the people.*

## ***Science***

Two opposing views about scientific research were expressed:

*Science is not complete knowledge. Science has much left to be seen, much like religion. Like there are religious dogmas, scientific dogmas exist.*

*For me, I see it all as a scientist. For me, it is pure research. ... [The] nature of man is to know more.*

## 4. Summary

In this section we make some comments about the focus groups, the themes they raised, and similarities and differences between the two ethnic groups.

Differences that were observed between the two ethnic groups might well be due to demographic differences in the compositions of the respective focus groups.

- There were differences in education level: among the African American participants, 85% were college graduates, while only 25% of the Latinos had college degrees.
- Moreover, 85% of the Latinos were women, while 60% of the African Americans were women.
- Annual household income varied greatly: 31% of the Latinos had incomes less than \$15,000, while the corresponding figure for African Americans is 5%; and 47% of the African Americans had incomes in excess of \$60,000, while none of the Latinos did. (See the appendix for income data.)
- Of the African American participants, 90% were older than 30, while the corresponding figure for the Latinos is 52%.

Thus, in addition to the noted gender differences, the African American participants tended to be older, better educated, and with higher incomes than the Latinos.

Perhaps the first point to be noted is that, as a group, the African Americans appeared much more comfortable than the Latinos with the process; they simply spoke more.

As noted earlier in the report, an initial question was asked of each group before an educational piece was presented. A natural question is to ask: Can before and after differences in attitudes or knowledge be detected from the transcripts? For the African American groups, the answer appears to be no. For some of the Latinos, however, there appeared to be uncertainty about the meaning of the word “genetics” before the educational piece. This could be due to language difficulties, or to education. Moreover, the Latinos appeared much more reticent about expressing an opinion before the educational piece, and this might possibly be a reflection of cultural and/or gender differences.

Many of the concerns and issues raised by the two ethnic groups (cloning, privacy, genetic testing, genetic engineering, genetic counseling, gene therapy, access to information and benefits, the role of government) were similar. We will concentrate here on differences that are apparent from the transcripts.

The African Americans were much more vocal in expressing the opinion that they, as a community, should be intimately involved at all stages of policy making, as well as active participants in genetics research. They also thought that they needed to be pro-active in their support of education, and in disseminating information in their communities. These views were much more muted among the Latino participants. This could be due to any number of reasons, among them education and cultural differences.

The African American groups expressed a far greater degree of mistrust of the role of government, perhaps because of previous medical experimentation.

An interesting contradiction is apparent, in both ethnic groups. Both African Americans and Latinos expressed, to varying degrees, distrust of government. There is a clear tension between this distrust and the need for government regulation in ensuring that genetic information is kept private and not be used to

adversely affect insurance and employment, and their communities are guaranteed equal access to information and the benefits of genetic technology.

## Appendix

### Education and income data

#### Latino groups

Location	Education				Total
	Did not graduate high school	High school graduate	Some college	College graduate	
Saginaw	4	4	3	0	11
Detroit	2	5	1	3	11
Grand Rapids	1	0	4	5	10
Total	7	9	8	8	32

(One person is missing in this table)

Location	Annual household income					Total
	<\$15K	\$15K-\$30K	\$30K-\$45K	\$45K-\$60K	>\$60K	
Saginaw	6	3	2	1	0	12
Detroit	2	4	5	0	0	11
Grand Rapids	2	3	2	2	0	9
Total	10	10	9	3	0	32

(One person is missing from this table)

#### African American groups

Location	Education				Total
	Did not graduate High school	High school graduate	Some college	College graduate	
Ann Arbor	0	1	1	8	10
Lansing	0	0	1	9	10
Total	0	1	2	17	20

Location	Annual household income					Total
	<\$15K	\$15K-\$30K	\$30K-\$45K	\$45K-\$60K	>\$60K	
Ann Arbor	1	2	2	0	5	10
Lansing	0	2	3	0	4	9
Total	1	4	5	0	9	19

(One person is missing from this table)