

**1999/2000 Focus Group Content Report:
Communities of Color & Genetics Policy Project
(Project Evaluation Team)**

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Introduction

The Communities of Color & Genetics Policy Project (CCGP) began with a series of focus groups conducted to ascertain issues and concerns related to the Human Genome Project that were particularly salient to communities of color. These focus groups were intended to solicit information about key concerns or dilemmas, which would then be used as key topics for discussion within a series of dialogue groups addressing these concerns. This report summarizes key issues and themes that arose within those focus groups.

Methods

A series of focused group discussions were held in seven communities in the fall of 1999 and the winter of 2000. The intent of these discussions was to ascertain salient concerns or issues within Latino and African American communities regarding the Human Genome Project and related activities. Focus group participants were recruited through community-based organizations affiliated with the CCGP, and the number of participants in the focus group discussions ranged from 5 to 12. (The recruitment process, and participants' satisfaction with the focus group process are described in more detail in a separate report, entitled Evaluation of Focus Group Process). Four focus groups were conducted with Latino participants, and five with African American participants between June and November, 1999. Income of the focus group participants was assessed based on self-reported income, categorized as follows: <\$30,000 for low income; \$30-45,000 middle income and >\$45,000 as upper income. Groups were classified as falling within one category if more than 60% of participants reported incomes within that category; they were classified as mixed income if less than 60% of participants fell into any single income category. Based on these criteria, one of the Latino focus groups was classified as low-income, two as mixed income, and one as high income. Of the five African American focus groups, one was classified as low income, three as mixed income, and one as high income.

Focus group facilitators and observers received two hours of training to introduce them to the project and to their respective roles in the focus group sessions. The observer's role was to record aspects of the groups' process (e.g. facilitator-participant interaction), and to record major issues raised by the groups. In addition, at the end of each focus group, the observer presented the key issues s/he had recorded during the focus group discussion. Participants had the

opportunity to suggest additional issues of importance from the discussion at that time. The facilitator then asked each participant to rank-order the five most important issues from the list. Based on these individual rankings, a rank ordered list of issues from each group was calculated.¹ This rank ordering, and the issues and themes thus identified, were to be used to guide topic selection in a series of dialogue discussions to be conducted subsequently in each of the participating communities.

Seven of the nine focus groups were tape recorded to capture the discussion in detail: the remaining two focus groups experienced technical difficulties with their recording equipment and recordings were not available. Tapes were transcribed and preliminary codes were developed from the transcripts using in-vivo restatements and building code categories from those restatements (Charmaz 1994; Chesler 1987; Glaser and Strauss 1967). Code categories were first developed to examine key themes that emerged within each of the focus groups. Then codes were combined across focus groups, merging in-vivo restatements from each of the groups to create integrated code categories that contained information across all of the participant groups. This process enabled us to examine the extent to which issues, concerns and ideas emerged across the African American and Latino focus groups, and also across areas of the country (e.g., Michigan and Alabama).

This report documents the key themes that emerged through this content analysis, and discusses the extent to which they appeared across racial or ethnic groups and across regions. In addition, we compare the themes that emerged through the process of content analysis with those that were derived from the ranking process described above. We discuss similarities and differences in the themes that emerged from each process, as well as strengths and limitations of each of the processes.

Summary of Focus Group Themes

“There is a lot of potentially good things.” Participants in nearly all of the focus groups described ways in which they felt that genetic testing and access to genetic information could be

¹ Rank orderings completed by each individual in a given focus group were numbered, then inverted in value, with 5 representing those issues felt to be of highest importance, 4 those of second highest importance, etc. Individual participant scores from 5 to 0 were then summed to yield a total group score for each issue. Within each group, the item that was ranked as their top priority (that with the highest tally) was given a group ranking of number 1, that ranked as their second highest priority (with the second highest tally) was given a group ranking of number 2, and so on down the complete list of issues. Prioritizations were thus a composite of the scores assigned by an individual for a given issue and the number of individuals assigning a particular score.

potentially helpful or useful . Among the potential benefits described in one or more focus group were the potential of genetic testing to help prevent illness or death through early detection of genetic concerns, and the potential for intervention to manage or treat those concerns. For example, a participant in one focus group noted:

I think of the genetic tests that can be helpful for planning for individuals having in mind to produce as a couple. Before-conception procedures (can indicate that they have) 50% change of this disease and want to make a decision as to 'we will or will not have kids.' That's something that some people might want to know.

Some group members emphasized that young people, particularly those of childbearing age, might benefit more than older members of the population from the availability of genetic testing and information. (Other themes related to differential benefits are discussed in more depth later in this report). Opportunities for screening and counseling for young adults (particularly women of childbearing age) were perceived as providing information necessary for informed decision making and choices regarding childbearing.

Other perceived benefits of genetic research included the belief that the information gained could be used to address important social problems, for example by bringing an end to world hunger through increased the production of food:

I believe that if the governments that have a lot of money will subsidize 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.

Similarly, some in other groups saw genetic information and genetic intervention as progress toward a utopian vision of a world free from illness or disease, an opportunity to “*better the human race in many aspects.*”

Within every group, however, discussion emerged that tempered such utopian visions. Participants in several groups raised questions about the limits of genetic testing. For example, some raised questions about the usefulness of genetic testing when cures or treatment for the conditions were not available. Others felt that genetic testing might offer a sense of security that was unwarranted, as in the following excerpt:

But genetics kind of give us a false sense of security in that sense. And the reason I'm saying that is because now you see more and more women having babies after 35 and on up. Because we're living in this false world of thinking modern medicine is so wonderful, we have learned to prevent the cause. But they don't understand that you can't prevent the cause, you can only identify and then proceed.

Here the focus group participant notes that the availability of testing for Down's syndrome has enabled women over the age of 35 who are bearing children to be tested and to make decisions about carrying the pregnancy to term. A decline in the number of children born with Down's syndrome might contribute to a misperception that the *risk of conceiving* a child with Down's syndrome has declined, when it has not.

Some focus group participants expressed concern that too much knowledge may not be a good thing. Participants pointed out that having information might force people to decision points that could exact heavy psychological, financial or emotional costs.

... But thinking about it then and now, you do wonder how much information is too much information for me, because it does take you to those decision points. You know, thank God it (experience with genetic testing) was positive for me, but if it was negative, where would I have been? It would have been better if I would not have known There are families that are faced with those decisions, and you really do say how much is too much for you, for a human, to handle?

Many participants viewed the potential benefits that might be derived from genetic testing and counseling with caution. One participant, for example, described the potential for genetic information to be used in both beneficial and detrimental ways, saying:

I think all deserves caution, but we aren't going to put the genie back in the bottle either. So the real question is, how can this information be controlled, and put in the right hands of whoever, and the right forms and do the right thing with it?

The idea that genetic information is not good or evil in and of itself, but has the potential to be used or applied in ways that may have positive or negative impacts, is explored in more detail in

later sections.

“People need information about it.” A theme that emerged across groups was that, if information gathered through genetic testing and genetic research were to be useful, groups must have access to enough information to enable them to make informed decisions. In nearly all groups, lack of information, or the inability to disentangle factual ideas from those based in myth or misinformation, were important concerns. For example, one participant described the importance of accurate information about genetics and heredity, in order to dispel beliefs that might be harmful to those with hereditary diseases:

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. At times they are genetic problems, and at times they are beliefs or religions -- that God must command, that God punishes. That is not true – they are genetic problems that can be inherited, and this is a very important topic to have more knowledge and (to) understand more of life and the problems that affect us.

Focus group participants viewed the assumption that everyone has access to information or awareness about both the potentials and the limits of genetic testing and counseling with skepticism. They expressed particular concern that communities of color would not have access to adequate information, and described strategies that could be used to ensure dissemination of this information across a range of educational levels and life styles.

We shouldn't make assumptions that everyone in our society is educated to a certain level, because we've got a lot of people who do not have the benefit of education except from the media. And we have to be very, very skeptical about what the media presents to people.

Focus group participants emphasized that information about genetic testing and genetic research should take care to address misinformation that may exist within the communities.

Above and beyond the need for accurate information to enable community members to take advantage of the opportunities afforded by genetic testing and genetic information, focus group members also emphasized that inadequate information, or confusion about existing

information, leaves people vulnerable to exploitation. That is, in order to make informed decisions that would adequately protect themselves and others in their communities, people need adequate and complete information about both potential risks and potential benefits.

Any genetic research information impacting Latinos should be fully disseminated within the community through the general media as well as community resources, such as organizations, churches and educational institutions. This information should, of course, be in a bilingual format.

The concern that communities of color would be less able to benefit from the results of genetic research because of inadequate information reflects broader concerns about the inequitable distribution of costs and benefits of such research. These are discussed in more detail later in this report.

“We need to grab hold of some moral values before we just keep pushing more and more.”

Several groups expressed concern that scientific knowledge was moving ahead too rapidly, without time or thoughtful discussion of ethical or moral issues or concerns related to that knowledge. For example:

We don't have the answers, the information – we don't know what to do with it. This nation is spiritually flowing and grabbing at anything.... But I think that there are a lot of spiritual issues that are just unsettled and they are just out there. I think we need to grab hold of some moral values before we just keep pushing more and more what we think is out there, and saying we will figure it out when we get there...

Some saw this as indicative of a growing disconnection from humanity, or from spiritual or moral guidance. These concerns were raised in particular, although not solely, with respect to concerns about the implications of cloning, with particular concern for cloning human beings. Several groups raised concerns about the human rights implications of cloning human beings, particularly for the cloned individuals and whether they would be accorded the rights of other members of society. Concerns were raised about the potential to clone or reproduce individuals primarily as a source of human tissue or organs for others, and whether, for example, cloned individuals might be denied constitutional rights.

However, not all those who referred to religious or moral frameworks felt that genetic information or knowledge was in conflict with those beliefs. For example:

I believe in the will of God and if the will of God is to leave this world, I'm going to do it in whatever way. But if God gives you the opportunity of saving your life with this method, he is giving you this material to use it to continue living.

Others voiced concern that genetic information and the use of genetic material were part of a larger trend toward reducing individuals to “statistics” and “probabilities”. There was concern that this would result in failure to consider individuals as whole persons, or as part of a larger social collective, contributing to a perceived weakening of the social fabric. Concerns that genetic information would be used to selectively value or devalue individuals were raised in nearly all of the focus groups. For example, concerns were voiced about selective abortion on the basis of genetic information, devaluing of individuals on the basis of the probability of their risk of genetic problems, and the creation of some humans or human parts for their use by others. Each of these potential uses of genetic information raised spiritual, moral or ethical concerns among focus group members, and were linked with broader social implications.

Some concerns related to the social structure were expressed as concerns about the family, with cloned individuals perceived as a threat to valued family structures, and to the social relationships that are structured around the family as a unit of social organization. A few focus group participants discussed potential social implications, or social judgements, that might be applied to an individual who made a decision about a potential partner on the basis of genetic information. Furthermore, social and economic implications of multiple births were raised in one group. On the other hand, some participants also felt that genetics could be used to reinforce nuclear family structures by establishing paternity, with its associations with responsibility for children and implications for biologically defined families.

“Do we have enough understanding, right now, to say move forward?” Participants in both Latino and African American focus groups voiced general concerns about whether the current state of genetic knowledge was sufficient to move ahead with testing and other forms of genetic manipulation. In particular, a number of concerns were raised about the potential for long-term effects of genetic testing and manipulation. For example:

I guess the other thing that worries me about this whole Human Genome thing is that we're, as a people, changing and altering what might be a natural, God-given balance of things. And that just kind of concerns me, in terms of where will we ultimately end up....

In addition, concerns were raised in some groups about the potential for human error, and about the moral grounds upon which decisions related to genetic information would be made. For example, focus group participants voiced concerns that decisions would be made on the basis of genetic information that would determine whether an individual was allowed to live or die (e.g. through selective abortion). Questions were raised about whether this decision should be an option, and the implications of allowing such decisions. Furthermore, focus group participants pointed to the potential that decisions could be made on false or incomplete information.

... when the baby was in utero, they said this child's going to have this disease. This child's going to die by the time he gets this age. This child is going to have this particular handicap. Well, that child is normal. So what if she had aborted?

Many of the concerns raised around this issue were linked to the potential enormity of the outcome, and the implications of making a decision based on misinformation. For example, some focus group participants pointed out that intervening in genetic processes could impact future generations, and some expressed concern about the implications of interfering with processes of evolution. For example, one focus group participant worried that:

Evolution will not continue, evolution will be basically stopped with the cloning of genes – we will not evolve as a being.

Each of the three African American focus groups, and none of the Latino groups, discussed potential benefits as well as concerns about genetically engineered food. While one group, referred to earlier in this report, noted the potential for increasing the stability of world food supplies through genetically engineered foods, each of the African American groups expressed considerable concern about genetically engineered or otherwise modified foods. Many of these concerns were related to the absence of information about short or long term effects of eating food that had been genetically manipulated.

The genetically engineered food that we're having, just seems to me that we're just altering the natural occurrence of what is.... I'm not sure how that's affecting my chemical make-up.

These concerns may be linked to concerns described elsewhere about the lack of adequate information available for individuals to determine the risks that may be associated with genetic manipulation, combined with mistrust of the information that is available.

Perhaps summing up this underlying theme, one focus group participant asked simply “do we have enough understanding, right now, to say move forward?”

“We don’t quite trust our scientists.” Many concerns were raised across all focus groups related to the use of the data derived from genetics research, and from genetic testing. In particular, concerns were raised about the uses of this information in ways that would reinforce or exacerbate existing social inequalities that currently affect African American and Latino communities in the United States. Within this broad area of concern, a number of specific issues were articulated.

Scientific knowledge is not neutral. Discussions within both Latino and African American focus groups emphasized that scientific knowledge is not neutral. Participants noted that knowledge produced within social systems that are inequitable tends to reflect and reinforce those inequalities. They explicitly linked scientific knowledge to social control, as in the following excerpts:

Science is not neutral, it is always directed at an objective. It is always directed at a group of people.... There exists the problem that if science has this face, if the science also has this dark face... how to control it and overall who is going to control it?

Further probing the ways that the results of scientific research might not be neutral, focus group participants expressed concern that some groups – specifically groups of color and/or low income groups -- would bear the brunt of the human costs of the research, and benefit less from the results. Specifically, concerns were voiced that groups with power would benefit disproportionately, while groups with less social or economic or political power would bear a disproportionate burden of the costs. As one focus group participant asked rhetorically, “who’s

going to be the guinea pig?"

Will people without money benefit from this research? Concerns were raised that, within a capitalist system, benefits of genetic research would privilege those with greater access to economic resources, and not be readily available to those with fewer resources. Communities of color were perceived as less likely to receive benefits of this research as a result of fewer economic resources, less access to the education necessary to make good use of the information, or through other processes.

We are already beginning to see that the benefits are going to be distributed by income.... Those people who can afford it will do it (genetic engineering of children) and those of us who can't will be excluded from the medical schools and other things because we won't measure up

The inequitable distribution of benefits was seen as reproducing existing inequalities that are fundamental to capitalist economic systems.

This is a system that produces poor people, it needs poor people, it needs manual labor, it needs people that are under (others) to move the machines. That's not going to change thanks to genetics.

I think (the uses of genetic information) are 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.

Focus group participants also felt that people who could not afford access to genetic technology would not benefit from the information to be gained. Some felt that the government should assume responsibility for paying for genetic testing to ensure access to the benefits of such research. At the same time, pessimism was expressed that this would be the case, as one participant noted *"society is moving more and more towards the government not paying for certain things"*

Will people of color benefit from this research? Focus group participants voiced numerous concerns that communities of color would not benefit from research being conducted. They noted that research “*need(s) a control group and an experimental group*”, and noted their concern that communities of color might be disproportionately represented in groups that would be exposed to greater risks and fewer benefits. There was concern that the results of genetic research would, at best, be less available to communities of color and, at worst, become the basis for the perpetuation or reinforcement of existing inequalities. Furthermore, there was also concern that communities of color would disproportionately bear the costs of such research. For example:

Historically, its always been the lowest person in society that gets tested. In American it was the African Americans, in Germany it was the Jews... we've got to be wary as who's going to be the guinea pigs on this deal and its probably going to be us.

One focus group explicitly made reference to historical patterns of health research in African American communities in justifying their suspicions about the differential distribution of the costs and benefits of research. Focus group members referred to the Tuskegee Syphilis Study to substantiate these concerns, as for example in the following excerpt:

We need to remember what they did to our men in Tuskegee, we need to remember what they did to the soldiers in California. We've got to be really careful anytime Uncle Sam comes to black folk and says let me help you.

Within the same group, other participants pointed to social and economic conditions that they felt differed from those that prevailed during the Tuskegee study, perhaps decreasing the probability of a recurrence of the Tuskegee study. African Americans were not alone in voicing this concern. For example, from one of the Latino focus groups:

... many of the programs 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 – on the contrary, they use them like a statistic.

(They're) probably going to want to clone perfect people, so what's going to happen to all of us that are not perfect? Concerns were raised that inequalities would be reinforced through the specific manipulation of genetic information and genetic material to reinforce social inequalities. These concerns included: that individuals or infants who were imperfect or did not meet the expectations of their parents might be aborted, or that communities of color, or groups who were labeled as susceptible to particular genetic concerns would be discriminated against, through selective cloning or fetal selection of individuals with characteristics considered desirable . For example, focus group participants expressed concern that “*everyone will want to be cloned with blond hair and blue eyes*” and that “*they're probably going to want to clone perfect people, so what's going to happen to those of us that are not perfect?*”

“Exactly what kinds of studies are they doing?” Linked to concerns about the inequitable access to benefits and the use of information to reinforce inequalities, were many concerns about access to and control of genetic information and genetic material.

Many questions were raised about the kinds of studies that were being (or would be) conducted related to genetic material, and the ends that information would serve. Focus group participants expressed mistrust of the United States government in a variety of ways. Within some focus groups, mistrust was framed in terms of disbelief that the government would have the best interests of African American citizens in mind, as “*not trusting anything the government does that's supposed to be helpful to black folks.*”

Mistrust of the government was also framed in terms that recognized the power of the government, the potential for misuse of information, and concerns about the lack of control or influence on the part of communities of color:

They get all this information and all of the sudden is the government going to go ahead and do it regardless of how we feel about it?

Others voiced concerns about the government related to imperial interests and their implications for individuals:

What if they make 100 (of me) so that they go to another country to kill civilians?... The government could be out there doing (making) so many (of you) and doing so many illegal things, who is going to come up – you!

However, the federal government was not the only source of concern or mistrust articulated by focus group participants. Concerns were voiced about the trustworthiness of medical researchers, pharmaceutical companies, and private research companies. Many of these concerns were linked to perceptions that profit motives would outweigh concerns for the well-being or human rights of study participants, while others were grounded in the perceived fallibility of decisions made by those individuals or organizations.

Within many of the focus groups, concerns were raised about potential uses of the information obtained through genetic testing or research by various groups. These included concerns that insurance companies might force individuals to be tested, and use either the results or a refusal to be tested as a reason to deny coverage.

On the one hand, I would like to know some of the genetic answers. I would probably like to know whether or not I am passing 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....

Some feared that the association of particular risks with a particular racial or ethnic group (e.g. sickle cell anemia with African Americans) would result in discrimination against members of that group in access to insurance.

As Latinos, for example, we have susceptibility to diabetes. Almost all of us have the genetics for diabetes. Or the people of color, the blacks, have susceptibility to high blood pressure. Beforehand (the insurance companies) already know that for being that race, they already have a predisposition to certain sufferings and they can reject you automatically, your employer, your health insurance.

In addition to the many concerns raised about vulnerability to loss of insurance coverage as a result of genetic testing, there were nearly an equal number of concerns raised about employment. There were real fears that employers with access to the results of genetic tests on

employees or potential employees, would respond by excluding individuals from employment opportunities. Focus group participants feared that if they were tested and were found to be at risk of a genetic problem they could be fired or not hired, or would lose insurance. They also feared that testing would become a prerequisite for insurance, and that a refusal to be tested would be interpreted by employers or insurance companies as an indication of a genetic condition, resulting in loss of employment or denial of insurance coverage.

“Who will have the power to make decisions?” Across nearly all focus groups, participants raised concerns about who would have the power to make decisions, and the potential implications of where that decision making power was vested. Decisions about who would be tested, when, whether they would be given an opportunity to consent before the tests were done, what would be done with the information, were all sources of concern. There was considerable mistrust or suspicion that genetic information or material would be used for purposes other than those for which permission had been granted. For example:

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

Concerns about access to information about the results of DNA tests were seen as having serious implications, including but not limited to those discussed above related to insurance and employment. Concerns about loss of control of the uses of the information were not inseparable from these concerns about the potential long-term individual and social implications. One participant wondered whether insurance companies who paid for genetic tests to be conducted would then “own” the results of the tests, and be able to make decisions about them without the consent of the individual:

Does the insurance company pay for all those (genetic) tests? Do they have the right to do what they want (with the results)?

The potential sale of genetic information was of concern to others. One participant questioned *“why do we think they're going to be so ethical and not sell the same data to insurance folks, to exclude possibly us?”*

While most discussion focused on the concern about information being released or out of the control of the individuals who had contributed the genetic material, some expressed different perspectives. For example, one focus group participant said:

I think there's public health concerns -- that has to be where your individual privacy has to be compromised for the greater good.

In addition to concerns about the control of access to information, were concerns about control of the actual DNA material and the uses to which it might be put. These concerns included concerns about the potential for individuals or groups to obtain genetic material and use it for purposes of cloning . Potential sinister uses of cloned people were raised, including the concern that some with access to genetic material might “*create people for their own purposes*” or clone “*people to control them*”.

Once again, mistrust of the United States government to regulate access to and the use of genetic material was raised by focus group participants. For example:

The important thing is the use, I really insist on this, the faces that are behind this.... (If) the FBI is going to make this federal bank, that so they have the archived fingerprints, the genes. The question is, who is going to control the FBI? This is not exactly my country, but in the United States there is an enormous tradition of secret projects, at all levels.

As noted earlier, focus group participants offered historical examples to justify their concerns about government secrecy or duplicity in conducting research. Focus group participants voiced concerns about who would have control of the DNA gathered through genetic testing, and questioned the motivations behind keeping and storing genetic material:

Why do they keep for so many years those samples of the kids that were born in the 60s until now? Why do they keep them and for what purpose will they use them?

The sense that genetic material would be banked and stored over long periods of time raised concerns about the potential for that material to be used for other purposes, and that research might be conducted at a later time to which the donor had not consented. There was

some related concern that this also opened the door for researchers to make use of genetic material in ways that the donors would not have consented to. Mistrust of the underlying agendas of those involved with genetic research, and concern that those who participated in the research might “consent” without adequate or accurate information, are reflected throughout the focus groups.

“We ought to focus on the benefits and guard against the dangers.” There was a wide range of opinion about the extent to which participants felt that access to, and the potential uses of, genetic material could be effectively managed. Some were optimistic that it was possible to guard against the potential risks or dangers. For example:

... we don't need to jump from what are the benefits of genetic research all the way to the dangers of human cloning. There's a lot in between there. And we need to come out of sessions like this, become cautious enough to identify the concerns and problems to that we can address them through some kind of policies as we go through those steps, and we ought to focus on what the benefits are and guard against the dangers.

Some suggested specific regulations that they felt would be necessary to manage or control genetic information and material, including the need for government regulation of private industry, the need to monitor genetic testing through formal oversight and licensing of genetic testing laboratories.

However, others expressed deep pessimism about whether government policies or other regulatory devices could effectively control or manage the use of genetic information or material. Concerns were raised about the effectiveness and the underlying motivations of government, and about the motivations of private profit motivated organizations. For example:

I don't think there are any controls. I think that (another focus group participant) is right and if this were something that were solely government sponsored and government funded, we would probably have some recourse. But at this point, from my understanding, there are private companies that are racing, trying to see if they can beat the government. Because that way they can use the information in whatever they see is the most profitable way. And I don't see the government, or us as the people pushing the government, as being able to forestall that.

Finally, two groups specifically raised concerns about the extent to which communities of color could/would have influence or control of these processes. Discussion about the specific need for communities of color to find ways to influence decisions about genetic research, and the ensuing uses of that research, are linked to themes discussed earlier regarding disproportionate burden in the research process, and unequal access to the benefits of the research. In the following section, themes from the focus groups that explicitly address the influence of communities of color are examined.

“What we need to make sure that we have people in all aspects of genetic research.” In several of the focus groups, participants’ lack of trust in formal regulating processes moved into discussions of potential alternatives. The need for communities of color to regulate or control information/research that is conducted within their communities, and to develop mechanisms to ensure that community members have access to the benefits of this research were aspects of these discussions.

A number of strategies were articulated for ensuring community influence, participation, and control of research generally, including research related to genetics. Most felt that it was not an option to simply refuse to participate in research, as this reduced the applicability of research results to communities of color and reduced the potential to benefit from those results. For example, one participant asked:

Are we suggesting that, for whatever reason, we not participate (in research)? And then the whole world revolves around and then they don’t know anything about how it is with Blacks.... I’m just wondering, are we going to make a serious effort to exclude ourselves from this and then when the ball’s rolling we’re like “what about us?”

Others suggested that, in order for communities of color to participate as subjects in research, it would be important to also participate as researchers. The need to train researchers of color was seen as an essential component of gaining influence in the research process, and ensuring that the benefits of research would return to those who participated.

Let’s support these PhDs who are minorities, and encourage our children to grown up and make a difference in that area. Instead of just being in the background... I’m saying let’s

be an active part. Let's be these scientists and let's make sure that if something's good going on that I'm included, that my race is included.

In addition to ensuring that communities of color are represented as research participants, and as researchers, there was also concern that communities find ways to ensure community participation in the research process by those who were not necessarily research scientists. Focus group participants argued that members of their ethnic communities ought to be involved in the “*research design, collection, analysis and evaluation of the data, and (in developing) policy recommendations from the Human Genome Project.*” Furthermore, concern was expressed that historically black colleges be supported as integral to the research process:

I want to see the Meharrys Medical Schools and Howard, Tuskegee, and those places continue to get support....

Focus group participants noted that academic centers often used communities of color to conduct research, but that the research results were not often brought back to the communities. For example:

Oftentimes our communities are a playing ground for academic centers who come to us only when they need something. When the semester is over, they disappear and we're not the better for having had them. (We should) foster partnerships between communities and higher educational institutions focused on a common vision and common goals.

Focus group members recommended that communities of color foster partnerships such as those described above, and also that they request results, access to data, and other benefits from research conducted in the community. Such benefits might also be requested by creating oversight committees responsible for monitoring research conducted in communities, helping to determine what is funded and who funds it. Both Latino and African American focus groups noted the need to foster partnerships in which community members played an active role in generating the vision for research and ensuring that their communities benefited from the research. The need to foster a sense of commitment to the community among the participants in such partnerships was emphasized. As one participant noted, its important to “*have a sense of community – not all the time being a person of color makes you have a sense of community, to*

look out for our people.

Finally, focus group participants felt that having influence in decisions made about the uses of genetic information and genetic material required more than participation in the research process, but active engagement in policy making processes. For example:

Make sure that we know who the policy makers are and what their views are on all of 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 that it's in the light. So whatever happens is in the light, and it's not we going along with just another level of trust that somebody else is taking care of the problem – I think all of us can do something.

Comparison of Focus Group Themes to Priority Issues Generated Within the Focus Groups

The themes described above were generated through analysis of the focus group transcripts. A comparison of these themes to the rank-orderings of issues generated by the focus group participants provides an opportunity to examine the material generated through the two processes and consider the relative strengths and limitations of each method. The themes generated within the focus groups, and rank ordered by participants at the end of each session, are shown in Attachment A. As can be seen, many of the general themes generated through the two processes were similar, although organized in slightly different ways.

The observer/focus group-generated themes had the advantage of a relatively fast turn-around, as they were generated and rank ordered at the time of the focus groups by the focus group participants themselves. One strength of this process is that it provided an opportunity for focus group members to not only discuss issues but also to provide some sense of which of these issues were of greater concern to them individually. This weighting of concerns is not directly accessible through the content analysis of the transcripts.

The observers' task during the course of the focus groups necessarily involves reduction of the content of the focus group discussion, as the observers attempt to capture and summarize key points while the dialogue is in process. Observers were asked to capture each issue as it arose in just a few words, and when appropriate to provide one or two lines of elaboration. Some also chose to keep running notes that followed the verbatim flow of discussion. In some cases,

observers reduced the key themes to a word or two (e.g. “privacy”), while in others, observers included notes describing in more detail the content of the themes (e.g. “genetic testing can have a profound impact on people’s lives, exacting intense psychological talk, disrupting family relationships, and unfairly jeopardizing employment and insurability”). The latter example provides much more detailed information about the content of the concerns expressed by focus group participants, and provides valuable assistance in interpreting the specifics of the discussion. Training and preparation of the observers in ways to document the key themes, as well as the importance of staying close to the language used by the participants, can contribute to the richness and accuracy of information generated through this process.

A content analysis of the transcripts offers an opportunity for close attention to the ideas, concerns and rationales for those concerns offered by focus group participants in the course of the discussion, in their own language. In addition, the content analysis, conducted with the luxury of a bit more time, allows connections between various themes to be made in ways that may not be available through the observers’ notes.

For the purposes of this project as initially planned, the themes from the focus groups were to be used to develop themes for more in-depth discussion during the dialogue groups. However, there was some concern both the with accuracy with which the truncated issues lists captured the underlying issues raised by focus group participants, and the extent to which concerns raised by the focus groups should determine the content of the dialogue groups. As already noted, the observers’ notes from the focus groups were short, capturing key themes, sometimes in the language of the participants themselves and sometimes summarized into other language. For example, categories derived from the observer form from one of the focus groups included “protect privacy”; “genetic testing does not benefit older people”; “who’s going to benefit?”; and “test information used against you” among other themes. These themes were ultimately reduced further as they were combined with themes from other groups, and the final list of categories that emerged from the observational process included: “misuse of genetic information”, “discrimination”, “mistrust”, “privacy”, “access”, “racial-ethnic concerns”, “consent”, and “cloning.” While providing a general sense of the issues that arose during the course of the discussion, these headings offer less in the sense of understanding the specifics of why people were concerned with these issues, or the particular forms that these concerns took.

In addition, community advisory board members strongly felt the focus group themes should be used to guide and supplement whatever themes the dialogue groups themselves came up with, but should not determine them. Initial codes categories derived from a content analysis of

the focus group transcripts were distributed to the facilitators of the dialogue groups. In some cases, the dialogue group facilitators shared these lists with the dialogue group participants and asked them which, if any, of those themes they would like to discuss in the course of the sessions. In other cases, dialogue group participants were simply asked what themes they wanted to discuss during the course of the sessions, drawing upon neither the coded content from the focus groups nor the ranked priority lists derived from the observers notes during the focus group sessions.

In sum, the rank ordering of issues based on the observers notes from the focus groups appears to have provided a quick and reasonably accurate sense of the major themes discussed in the focus groups and the participants' ranking of their priority or importance. Content analysis of the focus group transcripts offers additional, more detailed and systematic information about the issues raised and discussed, and how they are framed by focus group participants. This process, on the other hand, takes additional time. In instances where time is short and resources are limited, a reasonable compromise between accuracy, completeness and time constraints may involve careful training of observers in methods of capturing key content without interpretation, and, where necessary, listening to a tape of the transcript to fill in additional information. Use of this method will be most reliable and consistent across groups when observers are provided with clear, consistent and accurate instruction about what they are expected to record and how. Where resources are available and time allows, coding the transcripts systematically can offer a more complete rendering of the content. In this case, the process for extracting key themes from the focus groups and using them in the dialogue groups was modified in the course of implementation. Decisions about how to implement the modified process were made by the individual facilitators, and varied across the groups as facilitators sought to be responsive to the concerns raised by members of the advisory board and to the concerns of the dialogue groups themselves.

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