article

Informed lay preferences for delivery of racially varied pharmacogenomics

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Objectives: To understand public perceptions and opinions of three options for prescribing medicine: individualized genetic testing, race-based prescription, and traditional prescription. **Methods:** Focus groups in urban, suburban, and rural communities over-sampled for minority groups conducted from February through April, 2001 in Georgia. **Results:** Group members ($N = 102$) identified individualized genetic testing as providing the best quality of care (60% of talk turns; 75% in postdiscussion anonymous survey), but stipulated the need for protection from the invasion of privacy, discrimination, and prohibitive cost. Most individuals chose genetic testing because it provided individualized attention, and African-Americans indicated they would choose genetic testing even if the costs were high. Overall, individuals were suspicious of race-based prescription. Analyses for degree of suspicion revealed a main effect for race and an interaction effect for race and gender. **Conclusions:** If issues of cost, discrimination, and privacy are addressed, lay individuals prefer genetic testing as the basis for prescription of medicines that exhibit racially patterned response variation. ***Genet Med* 2003:5(5):393–399.**

Key Words: *pharmacogenomics, race, genetic discrimination, focus group methodology*

Research to determine the extent and impact of racially differentiated pharmaceutical response is both on-going and contested.[1–8] A central component of that research agenda should be the determination of patient and public policy preferences, not only because of the importance of patient acceptance to the success of any drug regimen,[9] but also because any feasible option of differential drug delivery is likely to raise serious social concerns.

It is difficult to assess a priori whether laypeople, especially members of minority groups, would prefer individualized genetic testing or race-based drug assignment. On the one hand, if drugs are to be assigned on the basis of genetic tests, concerns about privacy and genetic discrimination are well known and have been widely publicized.[10,11] Additionally, financial costs of individualized genetic testing, although currently uncertain, may be substantial.[15] Research suggests that African Americans may be especially suspicious of genetic testing.[12–14] All of these factors raise concerns that individualized genetic testing might not be a preferred option. If, however, physicians are to assign drugs based on presumed social identity, this treats the social categories of race as though they reflected uniform, discrete biological categories. African Americans and others have serious grounds for concern that such "singling out" based on race might be associated with differential health care and might promote generalization of discriminatory attitudes.[16] Given strong concerns about both genetic testing and racial targeting, it is difficult for policy makers to know how these competing values would be rank ordered by lay people, especially members of minority groups who would be most seriously affected, and therefore what lay preferences and likely responses would be with regard to policies that apply pharmacogenomics by way of individualized genetic testing, race-based assignment, or traditional methods that do not rely on genetics.

The issues are further complicated by the lack of a one-to-one correspondence between socially applied racial categories and the geography and history of human genetic differentiation.[6,16] For example, there is no uniform "Hispanic" genetic profile, Africans are characterized by high diversity rather than uniformity, and even persons from the most distant ancestral groups have the majority of their alleles in common.[8,17] Recent admixture further complicates racial assignment. Moreover, in most cases, it may be the case that the percentages of nonresponders to particular drugs, and the differences between groups in percentages of nonresponders, are so low as to make questionable the utility of racial assignment.[18]

Given these difficulties, an assessment of lay preferences is a crucial component of medical policy development. However, pharmacogenomics is a complex topic, not easily amenable to survey research methods because of the difficulty of explaining the issues over the telephone to large numbers of individuals with low science and health literacy. Consequently, a reactance format focus group, which provides instruction in basic concepts and scenarios to which lay people can react, provides a

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superior method for ascertaining public preferences.[19] Focus groups also allow participants to respond to issues with their own preferences, concerns, and language, as opposed to survey research, which requires participants to select from a closed, and usually limited, set of options, which might reflect researcher's worldviews rather than those of participants. Focus group methodology also allows exploration and understanding of reasons for preferences, because participants articulate not only their choices, but also the reasons behind those choices.[20] Finally, when a sufficient number of focus groups is used, and when participants are chosen carefully to represent target audiences, focus groups can provide a good window on general attitudes, despite relatively lower numbers, especially given the growing limitations on survey research due to increasingly high noncooperation rates. In this case, the format has allowed us to focus on groups who are likely to be most affected by the new approach to medicine, both because they have the largest diversity of alleles and because they bear the greatest social burden of stigma.

METHODS

Participant selection

In the Spring of 2002, 10 focus groups were conducted ($N = 102$): five with self-identified Black/African Americans, one with self-identified White/European Americans, two with approximately equal numbers of self-identified African and European Americans, one with self-identified multiracial persons, and one with self-identified Hispanics/Latinos. Moderators were matched by self-identified race, with one integrated group being moderated by an African American female and one moderated by a European American female. Sessions lasted slightly over two hours.

Participants were recruited from (1) an urban area, (2) a regional agricultural hub, and (3) a university town, all in the southeastern United States. Community advisory boards discussed what constituted their community and then nominated individuals who would represent the breadth of perspectives in their community. Those individuals were then called by research team members and invited to participate. They were told who had nominated them and were offered $50 to compensate them for time and expenses. Approximately 50% of the nominees were reached by phone before the total number of needed participants was reached, and of those, approximately 42% (150) agreed to participate. Of those who agreed to participate, 69% actually showed up at the session. In some cases, participants brought spouses or other acquaintances as additional participants, and these persons were allowed to participate. Participants were screened on initial telephone contact to ensure that they had only "lay" genetic knowledge, and persons saying that they had "expert" knowledge of genetics or "knew a lot" about genetics were excluded. Each participant provided informed written consent, and appropriate institutional review boards approved the research.

Session structure

Moderators used a common script to describe the basic background to the issues under investigation (available upon request). A visual presenter was used to illustrate the differential distribution of "versions of genes" among different groups and the possibility of different reactions to drugs based upon genetic differences. The moderators then used a common series of questions, which had been developed by the research team and revised by the three community advisory boards. Moderators included follow-up probes and revised question wordings to seek full exploration of the issues by as many participants as possible. The script asked group members to discuss each of three options in turn, exploring the advantages and disadvantages of (1) individualized genetic testing, (2) race-based assignment of medication, and (3) initial assignment of the same drug to all patients. The research group had previously identified a series of advantages and disadvantages for each option. If group discussion did not cover these, moderators were instructed to bring them up. In almost all cases, the groups covered all issues and additional ones on their own without prompting. Moderators then asked for additional options, the option the group members preferred, the reasons, and then for any suspicions they had about race-based prescribing (other questions are not reported here). Individuals were also asked for their preferences on a written follow-up survey at the end of the session to ensure a private means of response separated from potential group pressure.

Data processing

Upon the completion of the data collection, session videotapes were transcribed, and transcripts were corrected against videotapes. Data were divided into talk turns, which are defined as words uttered from when one respondent began talking until another respondent spoke. Itemizing the data by talk turns instead of by participants allows a fine grained analysis of the full range of reasons for choices, as the same individual may give many different reasons across the session. It also reflects a perspective that focuses on social discourse as the target of interest as opposed to simply individual preference. Coding schemes were developed from theory, issues described in the academic literature, and transcript readings. Two coders were trained for each coding scheme, and they independently coded talk turns into categories for each measure, with a Cohen's kappa of 0.60, defined as "substantial" by Landis and Koch,[21] established as a minimum acceptable indicator of intercoder reliability.

Statistical analysis

Descriptive statistics were produced for all variables, and all talk turns that were nongermane were excluded from analyses. One variable—degree of suspicion—was continuous and was analyzed using one univariate analysis of variance and the Tukey HSD post hoc analysis procedure. This ANOVA included race and gender of participant talk turn as the fixed factors and degree of suspicion as the dependent variable.

Table 1
Participant characteristics

Race		Gender		Income	Education
Black/AA	61	Female	67	14 < $25,000	2% < high school
White/EA	24	Male	37	36 = $25–50,000	24% HS graduate
Hispanic/Latino	7			31 = $50–75,000	38% some college
Multiracial	12			9 > $75,000	22% B.S./B.A.
					11% some grad school
					1% J.D.

$N = 104$.

RESULTS

Characteristics of the subjects

The characteristics of the subjects for the focus groups are given in Table 1.

Option choice

Respondents' expression of their preferred option choice was coded. Eight categories for this measure were examined: option one (i.e., individualized genetic testing), option two (i.e., race-based prescribing), option three (i.e., uniform initial prescription), additional options provided by participants, "don't know" (i.e., participants stating that they don't know which option to select), patient choice (i.e., the ability for patients to have a choice in deciding the best option), assessing other variables (i.e., discussion of other variables that could be used to determine how medicine should be prescribed such as age or family history), and unclear statements. A Cohen's kappa (κ) of 0.82 indicated excellent intercoder reliability.[21]

Eighty-three of the 138 germane talk turns (60%) indicated clear participant preference for genetic testing, 23 talk turns (16.6% of those expressing a preference) suggested that participants preferred no initial variation in assignment of drugs, and five talk turns showed a preference for race-based prescribing (see Table 2). All Hispanic/Latino talk turns selected individualized genetic testing, and no multiracial participants selected race-based prescribing. An anonymous closed question individual response survey administered after the session showed an even clearer preference for individualized genetic testing over the other options, with 75% preferring individual genetic testing, 4% preferring race based testing, 9% preferring no variation in initial drug assignment, 8% offering another choice (e.g., homeopathic or Eastern based medicine), and 4% not responding.

Option advantages and disadvantages

Four categories emerged as relevant advantages or disadvantages to the various options. Each is discussed in detail in the following sections.

Quality of care

Participants' statements about the quality of care offered by the individual options were classified within one of five categories: positive (e.g., drugs would work faster and/or more effectively, be safer, or be made available more quickly), negative (e.g., drugs would work slower and/or be less effective, be less safe, or would not be available in a timely manner), side effects (i.e., prescribing drugs under a given option would result in more side effects), unnecessary (option not needed), and impact of race (i.e., race would be a confounding variable that made an option not viable). A Cohen's kappa (κ) of 0.72 indicated strong interrater reliability.

Forty-two of 194 talk turns were coded as indicating a belief that the quality of care would be positive for genetic testing, compared with nine for race-based prescribing, and five for no variation. For example, one participant said "Option one. I would pay the extra money to make sure I'm getting what's best for me, you know, not based on my race or any other type of situation" (P#11-002). Nine talk turns were coded as negative for genetic testing, and one talk turn indicated that genetic testing might result in side effects. An illustration of the concerns about the negative effects of genetic testing is provided by a participant who asked, "can it take longer, you know to get what you need because of genetic testing?" (P#2-606). Race-based prescribing received the most codable responses ($N =$

Table 2
Option choice and option choice reason

	African American	European American	Hispanic	Multiracial	Overall
Option choice					
Individualized genetic testing	48	16	7	12	83
Race-based prescription	2	3	0	0	5
Uniform initial prescription	17	2	0	4	23
Additional option	5	1	0	2	8
Don't know	7	1	0	0	8
Patient choice	0	5	0	0	5
Assessing other variables	1	1	0	4	6
Unclear	13	13	0	7	33
Option choice reason					
Individualized care	20	6	1	2	29
Privacy	1	4	0	0	5
Cost	3	1	0	3	7
Positive racial implications	4	0	0	1	5
Negative racial implications	2	7	0	1	10
Tradition	6	0	0	0	6
Other	7	7	0	4	18

Categories are not mutually exclusive; distributions do not add up to 188 (option choice) or 95 (option choice reason) because nongermane talk-turns are omitted.

45), indicating that race would negatively impact its feasibility. As one person put it, "There are too many other factors involved. I can't see how you can prescribe medicine for an entire group of people. I don't see how you can do that" (P#8-004). Another agreed, "We're all Black. None of us are the same genetically" (P#8-012).

Although this group contained only persons identifying as African Americans, no racial differences were found for quality of care (see Table 3), as is illustrated by a European American who said, "you could be one of sixteenth Native American and still have the gene that causes the particular disease that only Native Americans get, so they would need working on."[8–12]

Privacy

Privacy represented concerns that an individual, organization, or group of people would violate the privacy of individuals under an option plan and use their medical information for their own purposes. Seven privacy categories were developed to capture the range of comments: insurers, pharmaceutical companies, doctors, other health care industries (i.e., hospitals, or any mention of "health" or "medical" industries), employers, government, and "other" (i.e., any mention of a "they" who would use an individual's medical information for nefarious purposes). A Cohen's kappa of 0.93 indicated very strong reliability. Concerns about privacy were raised only in connection with genetic testing. One participant indicated that it could result in "a huge invasion of privacy" (P#1-505), and another agreed, worrying that "would they take his genes like these credit card companies do and sell it to other companies." A third put it succinctly, "my genes are nobody's business" (P#1-605). Insurers and employers were not coded here in relation to privacy, but some talk turns coded under "discrimination" arise from privacy concerns (described later). Seven of 34 talk turns expressed fears that doctors would violate privacy, and five talk turns indicted pharmaceutical companies for violating privacy.

Cost

Expressed concerns about cost were coded into three categories: positive (i.e., a given plan would reduce costs for individuals or companies or be favorably treated by Wall Street), negative-patient (i.e., a given plan would cost patients more in terms of out-of-pocket costs, insurance premiums, or insurance copays), and negative-general (i.e., a given plan would negatively impact the economy, the health care or pharmaceutical industry, as well as coding for general indicators that a plan would be a poor choice in terms of cost). Forty-eight statements were coded for cost, and the Cohen's kappa was strong ($\kappa = 0.89$).

All groups indicated concerns that genetic testing would cost more. One participant, for example, noted that they would prefer individualized genetic testing, but that it would cost too much, saying "I think [option] one [genetic testing] would be ideal. . . .I think that it will be too cost prohibitive" (P#12-010). Concern about cost was almost equally divided between worry that such costs would fall on the patient ($N = 13$) and attempts to articulate concerns about supply and demand ($N = 16$). No significant differences for race were observed. The majority of talk turns devoted to maximum dollar amount for genetic testing indicated a willingness to pay between $101 and $1000 for genetic testing. For example, members of one group discussed a range of costs, setting tens of thousands as too high and easily agreeing that $150 was well within bounds, but recognizing that it depended on the severity of the illness and the ability to use trial and error as a lower cost alternative. One respondent summarized the discussion of what an individual might pay out of his or her own pocket in this way: "I would agree to that [$150]. I would not think that would be unreasonable. $600, I have a problem with. . . .. it depends, what he said, like on what you have. If it's cancer, I'm like, 'Okay, I'll give you $600, or 1000, or whatever'" (P#12-008). Other group members believed that, "Dollar amount should never be determined in a person's treatment" (P#8-014). Participants, on the whole, considered cost issues seriously, but weighed individualized medical care as worth substantial costs, especially for what they felt to be serious illnesses.

Table 3
Assessment of quality of care by option and race

	Positive	Negative	Side effects	Unnecessary	Impact of race
Option 1: individual genetic testing	42	9	1	8	2
Option 2: race-based prescription	9	13	14	1	45
Option 3: uniform initial prescription	5	11	23	0	11

Categories are not mutually exclusive; distributions do not add up to 194.

Discrimination

Statements of concern about discrimination were coded based on six different sources of threat: insurers, pharmaceutical companies, doctors, other health care industries (i.e., hospitals, or any mention of "health" or "medical" industries), extreme measures (i.e., a given prescription plan was a prelude to culture-wide versions of the Tuskegee experiment, genocide, or class warfare), and other. Cohen's kappa was perfect for discrimination ($\kappa = 1.0$).

Concerns about potential discrimination were exclusively made in relation to genetic testing and race-based prescribing. Twenty-two of 39 talk turns discussed discrimination under genetic testing. For example, one participant said: "that would be an excuse the insurance companies would use also, you know, to discriminate against a person being eligible for insurance, so that would be the justification for implementing this genetic plan, the doctors would be in on it, and the insurance come in, like they always are, they always, they work together" (P#10-002).

Eleven talk turns discussed discrimination under race-based prescribing. Fifteen talk turns discussed the possibility of ex-

treme measures (such as genocide), all of which were made by African Americans (see Table 4).

Option choice reason

The expressed reasons for participant preferences for particular options were coded into eight categories: privacy (i.e., concern that information used to prescribe medication will be available to others), despite cost (i.e., willingness to choose an option even if it is expensive), because of cost (i.e., viewing cost as prohibitive to a particular option), positive implications of racial categorization (i.e., placement into a precise racial category is beneficial or helpful to one's health care), negative implications of racial categorization (i.e., placement into a precise racial category is harmful to one's health care, usually because membership in a racial category is not easily distinguishable), individualized care (i.e., receiving specific care tailored to an individual and/or medication is prescribed based upon one's own physiological needs), status quo (i.e., maintaining tradition or the status quo in terms of prescribing medicine because it is successful), and other. Cohen's kappa for this measure was satisfactory at 0.67.

Twenty-nine of 95 talk turns showed a clear preference for individualized attention or care, most frequently identified with genetic testing (see Table 2). Selection of an option despite high cost appeared in 13 talk turns, whereas rejection of an option due to high cost appeared in eight talk turns. Maintaining the traditional prescription methods appeared in six talk turns, most frequently in association with Option 3. Seven talk turns centered upon positive aspects of racial categorization, and six talk turns focused upon privacy issues. Only African Americans and multiracial individuals explicitly expressed a preference for selecting an option regardless of cost, and only African Americans chose an option because of either positive racial implications or tradition.

Degree of suspicion

Because a key component of the successfulness of any genetic testing program depends upon participant willingness to take the drugs so prescribed, we explored the levels of suspicion participants felt about drugs that were specifically designated as having unique appropriateness for African Americans. Responses were coded into three categories: (1) no suspicion; (2) moderate suspicion; and (3) high suspicion. Cohen's kappa was satisfactory ($\kappa = 0.67$).

In the focus group discussions, gender differences do not exist with regard to degree of suspicion, but racial differences were found [$F\,(3,384) = 4.01$, $P = 0.008$, $\eta^2 = 0.03$, *power* = 0.84]. Hispanic/Latino participants expressed significantly more suspicion than European Americans, with African Americans and multiracial individuals not significantly differing from any group. A significant race and gender interaction was also present [$F\,(3,384) = 5.62$, $P = 0.001$, $\eta^2 = 0.04$, *power* = 0.94]. Hispanic and multiracial males appeared more suspicious about race-based prescribing than do any other group, and European males seemed less suspicious than all other groups (see Table 5).

Reasons for being suspicious

Reasons for suspicion were coded if high or moderate suspicion was evidenced in the same talk turn. Seven nonmutually exclusive grounds for suspicion categories were expressed: race discrimination (i.e., instances of racist acts and suspicions about racism in general), economic discrimination (i.e., racially labeled drugs would be discriminatory because of the cost of the drugs), race as cultural/environmental construct (i.e., problematizing the idea of a "pure" race and statements that argued that race is more about culture/environment than genetics), less effective (i.e., racially labeled drugs would be less effective than other drugs), damaging (i.e., drugs for certain races would be damaging to one's health), group action (i.e., participant felt that few or no African Americans would take the drug indicated for African Americans), and suspicions of the medical system (i.e., insurance companies and doctors). Intercoder reliability was satisfactory ($\kappa = 0.67$; see Table 6).

Racial (51 of 227 talk turns) and economic discrimination (53 talk turns) were the two most frequently cited reasons for suspicion about race-based prescribing. P#8-014 articulated these as linked concerns: "If I want to buy insurance, they going to use my bad credit to make my payments high, knowing I can't afford it, but that's how they do us. . .. you know you got bad credit for a reason, you don't make as much as a White, and you try and you struggling to make it, but they going to make it higher instead of lowering it. There's a reason my credit is bad but that is the same thing with the medication. We can't afford that and then they going to always charge like everything we get costs more."

The idea that racially labeled drugs would be less effective (35 talk turns) and that these drugs could be damaging to in-

Table 4
Participant concerns about sources and types of discrimination

	Insurance	Pharmaceutical	Doctor	Other health industries	Extreme measures	Other
Option 1: genetic testing	2	0	1	2	14	3
Option 2: race-based	0	1	1	4	1	4
Option 3: uniform prescription	0	0	0	0	0	4

Categories are not mutually exclusive; distributions do not add up to 39 because nongermane talk-turns are omitted.

Table 5
Degree of suspicion about Option 2 analysis of variance results for race and race × gender interaction

	Mean	Standard deviation
African American	1.94	0.844
European American	1.67	0.804
Hispanic	2.15	0.881
Multiracial	2.11	0.994
African-American Females	2.03	0.834
African-American Males	1.72	0.831
European-American Females	1.97	0.847
European-American Males	1.37	0.616
Hispanic Females	1.75	0.754
Hispanic Males	2.50	0.855
Multiracial Females	2.05	0.999
Multiracial Males	2.25	1.04
Overall	1.89	0.855

Cell sizes range from 28 to 216 for race and 8 to 149 for race × gender interaction. Values range from 1 to 3, with higher values indicating more suspicion.

dividuals' health (27 talk turns) were also fairly prevalent reasons for suspicion. Participants expressed these concerns through simple statements ("Because it's less effective," P#12-008) and more complicated accounts:

"That's why I say I'm very suspicious of this African American drugs. I don't think enough research has been done on African-Americans period to just be able to prescribe a drug just for us. I think more money and time put into research for Europeans, for White people. You know, and I just feel like they will get the better drug" (P#8–012).

European Americans and Hispanics/Latinos were more likely to cite economic discrimination than African Americans.

Table 6
Reasons for suspicion of Option 2 overall and by race

	European American	African American	Hispanic	Multiracial	Overall
Racism	8	30	4	9	51
Economic discrimination	27	21	4	1	53
Race is a cultural construct	1	6	3	0	10
Less effective	11	19	3	2	35
Damaging	5	16	3	3	27
Group action	0	2	0	0	2
Medical system	2	21	0	2	25
N/A	11	38	2	2	53

Categories are not mutually exclusive; distributions do not add up to 227 due to omission of nongermane talk-turns.

European Americans cited racism and medical system suspicion less than all other respondents.

DISCUSSION

After articulating and exploring the advantages and disadvantages of the conceivable alternatives, the majority of our participants of all racialized groupings concluded that individualized genetic testing was the best policy option. Although participants expressed the caveat that high cost, violations of privacy, and discrimination be adequately handled, concerns about individualized genetic testing seem to be substantially lower than concerns about race-based prescribing. Across racial groups, a desire for individualized care represents the primary reason that genetic testing is preferred. In terms of racial differences in option choice, African American and European American groups did not differ in their likelihood of selecting genetic testing. Our smaller group of Hispanics/Latinos selected only genetic testing. This finding suggests that the generalized suspicion of the medical establishment and genetics research in particular may be of lower concern to African Americans and other socially stigmatized groups than concerns about reification of race, inaccurate categorization of individuals, and the ability to target African Americans specifically through drug assignment. Most notably for implications for compliance with race-based prescription, respondents expressed high levels of suspicion about the efficacy and safety of drugs designated as preferred for African Americans.

Based on these results, as well as our qualitative reading of the transcripts, we believe that respondents appear to be in agreement with the idea that using race as a way to prescribe medicine is akin to "racial profiling,"[5] and that such approaches to applying the insights of pharmacogenomics would not be readily received by the patients it would be designed to serve. Our study offered three choices, and allowed participants to generate other options. However, the discussions presumed that individualized genetic testing was available, and it therefore did not directly compare the case of traditional medicine against race-based prescription. However, participants expressed strong suspicion of race-based prescribing, and this is especially true for individuals of nonwhite racial groups. Even if race-based assignment of pharmacogenomics does not become a standard approach to drug assignment, these findings have implications for current practices that use race as a diagnostic and prescriptive criterion. Such practices, when made explicit to patients or made public through discussion, may exacerbate the lack of trust in the medical care system by minority group members.

Numerous scholars have noted that the lay public forms active, accurate, and complex opinions about genetics.[14,22,23] This research supported those previous findings, as lay participants were able to articulate the potential advantages and disadvantages of the various policies, even though they were provided with only the most basic information. The lay public's concerns about matters of privacy, discrimination, and cost of genetic tests, their preference for individualized genetic testing,

and their aversion to race-based prescribing should be carefully considered as these and other related issues are confronted in the formation of medical policy about pharmacogenomics.

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