Development and Validation of Tools to Assess Genetic Discrimination and Genetically Based Racism

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Financial support: This project was funded by the National Institutes of Health (HG02191-02).

It is possible that communication from mass media, public health or consumer advertising sources about human genetics and health may reify stereotypes of racialized social groups, perhaps cueing or exacerbating discriminatory and racist attitudes. This research used a multifaceted approach to assess lay perceptions of genetic discrimination and genetically based racism (N=644). Two tools for use in strategic planning efforts associated with communicating about human genetics and health, the genetic discrimination instrument (GDI) and the genetically based racism instrument (GBRI), were derived. The GDI emerged as having five dimensions associated with lay perceptions of genetic discrimination. The GBRI was found to be unidimensional. Scale validation activities supported the tools' concurrent and discriminant validity characteristics. Significant differences between blacks and whites on the criminal control rights, social reproductive rights and employer rights factors as well as the GBRI were found. We recommend application of these screening tools prior to national dissemination of messages associated with genes and disease susceptibility, including school and university-based curricula.

Key words: genetic discrimination ■ instrument development ■ racism and genetics ■ racism ■ health communication

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An increasing number of public messages, including direct-to-consumer advertising for genetic testing and therapies, reference race as shorthand to capture scientific associations relating disease susceptibility and drug metabolism.[1] Media theory and research suggest a wide variety of stereotyping effects arise from the use of racial exemplars to illustrate specific issues.[2,3] Thus, public messages referencing race in association with advertising for genetic testing and therapies, RBGM may heighten racial stereotyping[4] and increase patient fears about genetic discrimination, with such concern limiting utilization of genetic testing and therapies.[5] Lay audiences who self-identity as black American as compared to white American may differ in concern about possible stereotyping and/or genetic discrimination associated with messages about genes and health based on the historical context and current health disparities that exist between blacks and whites in the United States. Too often, health interventions designed to address health disparity rely on stereotypes of racialized social groups, and in doing so, fail to place culture at the center of both theory and practice. This research examined both the nature of lay views associated with genetic discrimination and the effects of self-identifying as either black or white American on these perceptions.

GENETIC DISCRIMINATION

We stand at the threshold of a world in which knowledge about the genetic make-up of human beings may afford great opportunities to intervene in disease processes. The most notable benefit of human genetic research and the Human Genome Project (HGP) for the public may be the ability to identify the presence of a gene associated with disease, so that one may thwart the development of a deadly, debilitating and/or disfiguring illness.[6] With these opportunities, however, come significant responsibilities which must also be systematically

addressed. Current and prospective uses of genetic testing for diagnosis and prevention have raised concerns not only about life and health insurance discrimination[7-9] but also about stigmatization and heightened racism.[10,11] Concerns about genetic discriminatory attitudes and effects are well-founded, as suggested by Nelkin and Lindee,[12] who indicate that, "If an employer, or educator or insurer can make the case that the 'predicted' future status of their client matters, then discrimination—denial of opportunity for medical care, work or education—can occur with impunity. Indeed, predictive genetic typing may create an underclass of individuals whose genes seem to have marked them for the nowhere track" (p.167).

Fear of discrimination often enters into individual decision-making about whether to seek genetic tests.[13] A variety of legislative efforts have been undertaken to try to mitigate issues related to direct abuse associated with genetic information and discrimination.[14] These policy efforts may also reinforce individual fears or uncertainties associated with reproductive freedoms that arise from lay perceptions, foreshadowing concern that individuals with particular genes may be precluded from marrying or bearing children.[15] The lay public may have well-formed attitudes about genetic discrimination in regard to genetics, genetic testing and genetic information. Individuals may, in fact, generalize understanding about a genetic component of physical diversity among races to a genetic component of behavior.[16-18] Little systematic inquiry has been done, however, to evolve understanding of lay audience frameworks for genetics, race and discrimination despite the reality that in an era of gene identification, discussions about genetic health issues can pose challenges associated with a variety of psychological, social and societal issues.

PSYCHOLOGICAL DIMENSION

A long history of noncompliance in medicine supports the vital role played by health beliefs on health behavior. Current levels of adherence to drug regimens, for example, are low. An analysis of compliance rates reported in studies of heart disease as one illustration showed that only 31–66% of patients stayed in care, between 31–58% took prescribed medications as directed, 40–50% followed prescriptions for activity, and between 13–76% followed prescribed diets.[19] An analysis by Mar and Rodriguez-Artalejo[20] asked "which is more important for the efficacy of hypertension treatment: hypertension stage, type of drug or therapeutic compliance?" The study concluded that strategies which lead to improved compliance would have the greatest returns in effectiveness and efficiency. In recent research associated with understanding lay attitudes about race-based prescribing, participants revealed strong belief that drugs which are preferentially assigned to minority groups are less safe and less effective.[5,21] If lay people are suspicious of the safety or efficacy of a drug because of perceptions that treatment recommendations are based on population indicators rather than the individual, they may be more likely to terminate treatment early on the basis of side effects or short term lack of perceived effect, all other things being equal (e.g., insurance). Such lack of compliance translates directly into lack of medical efficacy.

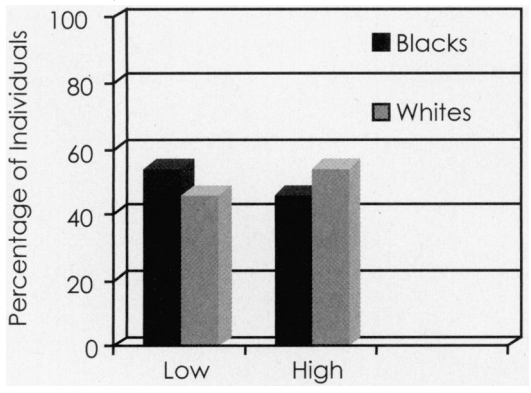
Table 1. Characteristics of Participants (N=644) for Development of the Genetic Discrimination Instrument (GDI) and the Genetically Based Racism Instrument (GBRI)

Characteristic	Overall	Percentage (%) Blacks (n=276)	Whites (n=309)
Education			
Less than high school	4.5	5.8	3.2
Completed high school	17.2	15.6	18.1
Had some post-high school	38.2	42.8	35.9
College graduate	24.2	23.2	24.6
Postgraduate	15.2	12.7	18.1
Income (Annual)			
<$20,000	9.2	10.9	6.1
$20,000-34,999	14.1	19.2	10.4
$35,000-49,999	17.4	19.2	16.8
$50,000-74,999	18.6	19.9	18.1
$75,000-99,999	12.4	9.1	15.2
$100,000 or more	10.6	6.9	13.9
Don't know	12.4	10.1	14.2
Refused	3.9	4.3	4.2

SOCIAL DIMENSION

Genetic diseases or disorders could lead family members to blame their immediate or extended kin for their current genetic health status.[22] In theory, no single family member "owns" genetic information, because every member could potentially share certain genetic traits, links or diseases. As a result, disclosure of this information can be difficult to negotiate. Yet, the timeliness of disclosed health information may affect how individuals manage the information because a limited "window of time" may exist for the maximum benefits of disclosure to be realized. Immediate or delayed disclosure can have a variety of consequences for the "teller" and the "receiver." For example, couples planning their families would likely prefer to be informed of any genetic risks prior to the onset of pregnancy. Discovery of a genetic disorder after conception could lead to familial tensions as a result of genetic inheritance not being disclosed at a time that assists in informed decision-making regarding the pregnancy. Thus, when one member of a family is diagnosed with a gene that has been identified as a contributor to disease, the entire family is affected. In the past, single gene disorders dominated the landscape associated with genes and health. The HGP, however, makes possible the identification of genetic contributors to most diseases. Family communication patterns associated with single gene disorders may lay a framework for response to genetic disorders more generally. Moreover, the higher rate of sickle cell disease among black Americans as compared to white Americans, coupled with the fact that black Americans are sometimes less likely to receive proper treatment and/or medical attention for diseases than white Americans,[23] leaves black Americans families in a "double-bind."

Figure 1. Comparison of the distribution of blacks and whites within groups who report low (n=290) or high (n=295) levels of agreement on the criminal rights dimension of the GDI; median= 2.00 on a five-point Likert-type scale.



SOCIETAL DIMENSION

Levels of trust in physicians are already precariously low, as indicated by a recent study by Corbie-Smith, Thomas and St. George.[24] Among other markers, their study showed that 45.5% of black American and 34.8% of white American patients thought that their physicians exposed them to unnecessary risks. Race-based genetic medicine (RBGM) may further erode trust in physicians due to the high level of belief that racially designated medicines for minority groups are unsafe and ineffective. Not only will this erosion of trust impede adherence rates, but, additionally, if people with illness do not trust their physicians, they may also attend alternative practitioners, self-medicate or use prescribed medicines tentatively and suspiciously, impeding results. Physicians are not going to be able to "hide" the fact that particular treatments are racially designated, and efforts to gain more specificity in medical history-taking about ancestry will heighten these sensitivities, especially in the presence of direct to consumer advertising associated with RBGM. These issues are magnified again when we think about efforts to incorporate "race" into public health messages about genetics.

GENETICALLY BASED RACISM

The net social cost of RBGM, were the science found to be sound, may still be too costly if it increases racism in the United States. While official messages with mitigating statements may be generated that forestall negative impacts from those specific messages, it is unlikely that all messages generated about RBGM by the press and other sources will carry such mitigators. Consequently, the net effect may be seriously harmful. These negative impacts may in turn adversely relate to clinical effects in areas of medicine unrelated to RBGM. As the IOM report, *Unequal Treatment*,[25] documents, one of the underlying causes of health disparities is racial discrimination, or racism, with reciprocal causal relations occurring such that those who experience such discrimination sometimes avoid care even when it is available.[26] Consequently, in order to produce a net health gain, the level of clinical benefit from race-based medicine will need to be greater than the clinical deficits created as well as greater than the general social harms created. The burden of proof for net benefit should be on those who propose to implement RBGM. If some racial or ethnic groups have a greater predisposition to have a condition/disease traditionally linked to genetics, it may contribute to patterned concealment. On the other hand, in this era of genomic healthcare where single gene disorders are being rapidly displaced by awareness that multiple genes contribute to many common diseases, including cancer and heart disease, family history related to these

conditions may lead the family as a unit to conceal this information from others (i.e., friends, employers, etc.) for fear of discrimination or stigmatization. Or, families may begin to traverse a course associated with recognition that everyone has genes linked to illness and disease and that knowledge of one's family history may be the best defense against harms associated with these biological characteristics that predispose one to ill health.

The public debate about the relationship between race and genetic information still exists,[27-29] providing a foundation for black Americans to perceive a climate for racial discrimination based on genes. Also, fueling feelings of mistrust is the current reality that health disparities exist between blacks and whites,[25] with recent studies showing that blacks are sometimes less likely to receive proper treatment and/or medical attention for disease or illness[30] and have greater health risks (e.g., cancer death rates, breast cancer and cardiovascular disease) than whites.[31] Current health disparities, personal experiences and a history that includes Tuskegee[32] are likely to contribute to a greater perceived risk of genetic discrimination based on race.

In sum, lay perceptions of the societal, cultural and personal norms related to race and genetic risk might form reliable patterns that physicians, health promoters and policymakers should understand to guide communication and message design. To identify lay perceptions associated with genetic discrimination, evolve a tool to assess these perceptions and consider possible differences associated with racialized social group perceptions of genetic discrimination, the following questions were posed:

RQ1: What lay models represent perceptions of genetic discrimination?

RQ2: Do blacks as compared to whites differ in views about genetic discrimination?

METHOD

This research was conducted in three phases: 1) formative research, 2) pilot study and 3) instrument development.

Formative Research Phase

This phase of the study involved 15 focus groups conducted with 120 participants who had not previously undergone genetic testing and had little knowledge of human genetics as assessed by screening questions during recruitment. Focus groups were used for their value in "learning how respondents talk about a phenomenon of interest" (p. 15),[33] and collecting preliminary information about health phenomena at the aggregate level.[34] The purpose was to find linguistically and culturally appropriate statements of the lay public's perceptions related to genes, health and discrimination. Focus group questions stemmed from a literature review of relevant information, a prior genetic discrimination scale[35] and discussions with three culturally diverse community advisory boards comprised of citizens and representatives of community organizations (including libraries, churches, schools and public health) to promote the participatory nature of the project. All focus groups lasted approximately two hours and included 60 persons self-identifying as blacks, 52 whites, seven Hispanic/Latinos, and one Tamarean/Native American ranging in age from 18 to 51 years (M=32.6)[36]. Focus group discussions from the formative research phase were content-analyzed by trained coders who were listening for statements about genes and race, and genes and discrimination concerns. This resulted in the emergence of 48 unique statements about the nature of genetic discrimination and genetically based racism.

Pilot Study Phase

The second phase of the project consisted of pilot-testing the statements derived from the formative research to assess audience perceptions of clarity and meaning. The goal was to refine content for items to be used in the population-based survey. The content of the questionnaire was reviewed by the three multicultural community advisory boards that included men and women from varied backgrounds (as described in 36) as well as a population geneticist and genetic counselor who considered content validity. Readability was assessed using the Flesch-Kincaid index and found to be at the 8.6 grade level. The items were then pilot-tested using five-point Likert scales anchored by 1="strongly disagree" to 5 ="strongly agree" to assess perceptions of clarity, believability, comprehensibility and complexity as well as the emotions experienced as a result of exposure to the statements, including anxiety, fear or anger.

The pilot study involved 149 participants recruited from a large land grant university in the southeast, with 58.5% being female and 41.5% male. The majority of the sample self-identified as white (83.8%), with 6.3% self-identifying as African-American, 4.2% as Asian, 3.5% as bi-/multiracial, 1.4% as Hawaiian/Pacific Islander and 0.7% as other. These participants completed self-administered surveys and provided written confidential feedback in response to several open-ended questions about the perceived sensitivity associated with the questionnaire's content.

In view of the reality that whites as the majority race in the United States are the race most often accused of racism and discrimination with regard to race, we were particularly interested in attaining their perceptions and reactions to the content of survey

statements. Thus, our primary goal was to gather insights about perceptions to promote our ability to construct survey statements to which people would respond honestly, avoiding to the extent possible the termination of interviews in the population-based survey because of the sensitive nature of questions.

Pilot study participants' ages ranged 19–40 years (M=21.66; SD=2.35). While participants perceived content to be sensitive, they did not react to it as being unduly so; content revisions primarily centered on feedback about the seeming redundancy associated with the survey items.

Instrument Development Phase

The third phase of the project centered on the development of measures of genetic discrimination and genetically based racism. A 103-item questionnaire was derived based on the formative research and pilot study results, and including the following scales added to validate the measurement model: 1) the

Table 2. Factor Loadings for Genetic Discrimination Scale

Factor	EMP	CRM	INS	SOC	IND
Employers should have the option to not hire someone with a genetic disease.	**0.57**	0.05	-0.13	0.11	0.18
Employers should be permitted by law to use genetic information when making hiring decisions.	**0.54**	0.09	-0.14	0.09	0.21
Employers should have the option to not hire someone who is more likely than average to get a genetic disease.	**0.78**	0.003	-0.18	0.09	0.21
All persons who are arrested should have their DNA put on file in police departments.	0.06	**0.81**	-0.03	0.05	0.07
All persons who are convicted of crimes should have their DNA put on file in police departments.	0.07	**0.82**	0.02	0.07	0.02
Insurance companies should not treat those who have genetic flaws differently from other people.	-0.08	-0.01	**0.37**	0.04	-0.07
Insurance companies should not discriminate against those who have a genetic defect.	-0.06	-0.02	**0.51**	-0.02	0.01
Insurance companies should not be able to discriminate against those who have genetic flaws.	-0.09	0.05	**0.53**	-0.01	0.01
Insurance companies should not refuse coverage to people who are more likely than average to get a genetic disease.	-0.02	0.02	**0.51**	-0.04	-0.01
Insurance companies should not discriminate against those who have genetic diseases.	-0.10	-0.06	**0.61**	-0.01	0.02
Physicians should advise all prospective parents who have genetic flaws against having children.	0.12	0.05	-0.04	**0.67**	0.27
Physicians should be permitted to advise all prospective parents who have genetic defects against having their own children.	0.13	0.04	0.01	**0.66**	0.22
Physicians should advise all prospective parents who have genetic defects against conceiving children.	0.06	0.07	0.004	**0.73**	0.21
I would not want a child of mine to marry someone with a genetic flaw.	0.12	0.01	-0.02	0.18	**0.71**
I would not marry someone who has a higher than average risk of getting a genetic disease.	0.17	0.03	-0.02	0.09	**0.75**
I would not marry someone who has a high risk of getting a genetic disease.	0.19	0.02	-0.08	0.14	**0.79**
I would not marry someone with a genetic flaw.	0.17	0.04	0.02	0.15	**0.75**
I would not want my child to marry someone with a genetic disease.	0.09	0.01	-0.02	0.21	**0.77**
I would not marry someone with a genetic disease.	0.09	0.06	0.002	0.10	**0.78**
I would not want my child to marry someone with a higher than average risk of getting a genetic disease.	0.12	0.01	-0.004	0.18	**0.69**

EMP: employer rights; CRM: criminal control rights; INS: insurance company rights; SOC: social reproductive rights; IND: individual reproductive rights

Modern Racism Scale,[37] alpha (α)=0.78 (MRS); 2) the Racial Denial Scale[2] α=0.68 (RDS); and 3) the Motivation to Control Prejudice Scale,[38] a =0.85 (MCPS). Four versions of the final survey instrument were created to control for possible effects associated with the order of responding to questions.

Procedures and participants. Data were collected via telephone through the use of random digit dialing (RDD) procedures with oversampling of area codes associated with high proportions of black residents designed to obtain nearly equal representation of both blacks and whites. The phone survey was administered by a professional survey research center and utilized trained interviewers and a computer-assisted telephone interview (CATI) system. After introducing her/himself, the interviewer introduced the survey in the following fashion: "We are assisting a professor here at the university in conducting an opinion survey about genes and health, and you have been randomly selected to participate. All answers that you give us will be completely confidential. The survey will take about 10 minutes of your time. In order for the results of the survey to be representative of the state's population, I need to speak with the youngest male 18 years of age or older who lives in the household." If the potential participant responded that he met this criterion or sought the participation of someone in the household who met the criteria, the survey continued. If the potential participant responded that there was no one in the household who met the requirements, the interviewer asked, "May I speak to the oldest female 18 years of age or older?" By this introduction, efforts to obtain male participants and older female participants were enhanced. If an eligible person indicated that they did not have time at the moment, the interviewer sought to set up a callback time. Participants were told that: 1) five individuals would be randomly selected to receive $50 for their participation, 2) all information would be kept strictly confidential, 3) participation was completely voluntary, and 4) they did not have to respond to any question that made them uncomfortable.

Participants were also told, "My supervisor may also listen to part of the interview for quality-control purposes. The questions that we are asking you do not reflect our opinions on the subject, and some of them may not reflect your attitudes either. There are no right or wrong answers. We ask such a wide range of questions in order to be sure that we capture the full range of attitudes. We hope you will feel free to give us your own honest opinion." The overall response rate for the completed survey (N=644) was 35.1%, using the completed interviews as a percentage of the contacted, including eligible refusals and partial interviews. This level of response is a reality observed in other survey research and is attributed to the increased number of solicitations by phone and the response gaps associated with software packages that work with CATI to match a live interviewer with a live respondent but too often leave someone on the phone listening to silence.[39] The nature of a study also contributes to the completion rate, with the sensitive nature of the questions asked in this project, including

Table 3. Factor Loadings for Genetically Based Racism Scale

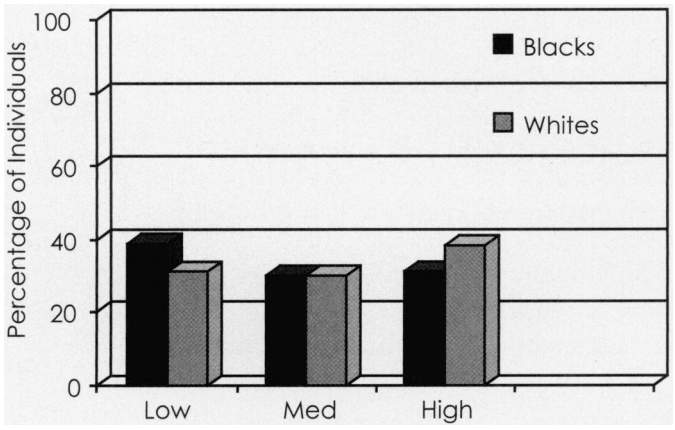
Racial differences in academic ability are caused by genetics.	0.71
Members of one racial group are more artistic than members of another racial group because of genetics.	0.75
Members of one racial group have more mental illness than another racial group because of genetics.	0.64
One race may be stronger than another because of genetics.	0.75
Members of one racial group are stronger than members of another racial group because of genetics.	0.69
Members of some races may not be able to do some things as well as other races because of their genetic makeup.	0.68
Genetics can cause members of one race to be better at certain things compared with those of another race.	0.71
Members of one racial group are more musical than members of another racial group because of genetics.	0.70
Members of one racial group are more ambitious than another racial group because of genetics.	0.74
God gave some races genes that make them better at some things than other races.	0.59
Members of one racial group have more scientific ability than another racial group because of genetics.	0.78
Genetics causes differences in intelligence.	0.72

items about racism and measures for validity purposes, which likely contributed to a lower response rate, a finding consistent with previous survey research.[40] In this research, findings may actually be conservative in nature, as respondents may have avoided more extreme responses by refusing to participate, failing to complete participation or tailoring responses in a socially desirable direction. Surveys were completed by 644 randomly selected adults from the state of Georgia, with 224 of these individuals having provided contact information at the end of the survey to allow their names to be included in a random drawing for one of five $50 cash incentives. There was nearly equal participation by whites (48%) and blacks (43%) obtained by targeting area codes known to have a high percentage of black American residents. The remaining participants self-identified as biracial (3%), Hispanic (1%), Asian (0.5%), Native American (0.3%), and other (2%) or refused (2.5%). Among participants, 65% were female, with ages ranging from 18 (3.4%) to 87 (.2%) years of age and a mean of 43.2 years (SD=16.82); the average age of black participants was 41 years, and 44.5 years for whites. Income and education information is included in Table 1, including the baseline characteristics of black and white participants.

Data analysis. The Statistical Package for the Social Sciences (SPSS) was used to conduct exploratory factor analysis, an appropriate method for data reduction when a grounded theory approach has been used as was the case in this research. Criteria for factor and item retention were: 1) eigenvalues >1.0 for retained factors, 2) primary factor loadings of ≥0.50 with the exception of one item that had theoretically meaningful content, 3) use of the Scree test to assess relative increase in variance accounted for, and/or 4) interpretability of the resultant factor structure. Prior to conducting the analyses, items were reviewed for nonnormality and eliminated if they demonstrated high levels of skew associated with ceiling or floor effects, or kurtosis greater than or less than -2–+2. An exception was made for two items that related to previous genetic discrimination research that had high face validity. These were: 1) insurance companies should not be permitted to discriminate against those who have genetic flaws; and 2) employers should have the option to not hire someone who is more likely than average to get a genetic disease. As a result of the previous step, 10 items were removed from further analyses (e.g., "Schools should not have access to a child's genetic tests without permission from a parent"). In general, all participants strongly agreed with this statement (M=4.51; SD=1.09). Principal axis factoring with varimax rotation was selected toward the aim of creating a parsimonious representation of the data and factors to be extracted from statements about genetic discrimination.

Results. In response to the first research question, a five-factor solution for the genetic discrimination instrument (GDI) emerged as the most parsimonious structure, including 20 items that accounted for 50.11% of the variance (Table 2). The five dimensions of genetic discrimination included: 1) a seven-item individual reproductive rights factor (M=2.21, SD=1.14; S^2=26.47%, α=0.91); 2) three-item social reproductive rights factor (M=2.83, SD=1.32; S^2=8.09%, α=0.78); 3) three-item employer rights factor (M=1.64, SD=0.95; S^2=6.82%, α=0.72); 4) five-item insurance company rights factor (M=4.23, SD=0.85; S^2=5.07%, α=0.63); and 5) a two-item criminal control rights factor (M=3.26, SD=1.57; S^2=3.18%, α=0.81). The statement, "Insurance companies should not treat those who have genetic flaws differently than other people," was retained to increase reliability of the fourth factor (α=0.63). Some factors were weakly correlated, but only two exceeded the standard criterion of 0.32[41] (Table 4), with logic supporting the connectedness of these dimensions. One might expect, for example, that perceptions of individual reproductive rights would be related to social reproductive rights, but personal, organizational and policy implications would be diminished if only a reproductive rights factor were retained. The model's parsimony, minimal evidence of high correlation and theoretical significance of the extracted fac-

Figure 2. Comparison of the distribution of blacks and whites within groups who report low (n=204), medium (n=177) or high (n=204) levels of agreement on the social reproductive rights dimension of the GDI. The distribution of responses revealed three nearly equal groups, with a neutral range from 2.33 to 3.33 for the middle group, a range in responses from 1 to 2 the low group, and a range in responses from 3.67 to 5 for the high group.



tors contributed to retention of the factor solution. A separate unidimensional 12-item scale was formed demarcating the genetically based racism instrument (GBRI) (M=1.98, SD=0.99; S^2=49.90%, α=0.92) (Table 3).

The participants who provided contact information were compared with those who declined to provide such information to consider the possibility of systematic differences in responses. When comparing participants who provided contact information for the cash incentive drawing with those participants who declined to provide contact information, only one significant difference was found. Those who did not provide contact information had more negative attitudes (M=3.12, SD=1.58) about granting police access to DNA relating to the criminal control rights than those who provided contact (M=3.58, SD=1.51) information (t(503)=3.15, p<0.01).

Concurrent and discriminant validity. At the conceptual level, attitudes about genetic discrimination and genetically based racism should relate to attitudes about racism in general. The employer rights and criminal control rights factors correlated weakly with the MRS (r=-0.11, p=0.02; r=-0.14; p<0.01), respectively supporting the concurrent validity of those two factors. The insurance company rights, individual reproductive rights and social reproductive rights factors were not correlated with the MRS, supporting the discriminant validity of the GDI. The GBRI also did not correlate with the MRS, indicating that genetically based racism is not isomorphic with racism. All factors of the GDI and the GBRI correlated weakly (r=0.10, p=0.05) to moderately (r=0.27, p<0.001) with the RDS, supporting concurrent validity. The criminal control rights and insurance company rights factors were weakly correlated with MCPS (r=0.08, p=0.04; r=0.15; p<0.001). In total, these standardized tools thus afford a broader conception of lay perceptions of genetic discrimination than past instruments. They include insurance discrimination but reveal several related grounds on which discriminatory judgments linked to genes may rest.

In response to the second research question, we found significant differences for levels of income between black and white participants (t(583)=4.24, p<0.001) and nonsignificant differences for education (t(583)=1.70, p=0.09). Both income and education may contribute to perceptions associated with GDI and GBRI. Thus, we controlled for the possible effects of income and education on participant views before assessing a role for participants' self-identification as black (n=276) or white (n=309) on perceptions. As illustrated in Figure 1, findings supported differences for criminal control rights (t(583)=2.27, p<0.05), with blacks (M=3.11, SD=1.61) evidencing more concern about the collection and use of DNA for police use than were whites (M=3.40, SD=1.50) after controlling for the significant effect of education (r=-0.20, p<0.001); more education was associated with less support for granting police access to criminals' DNA. Findings supported the significant effect of income (r=-0.13, p=0.001) and education (r=-0.11, p=0.004) on perceptions of social reproductive rights. After controlling for these variables, a significant effect for race was found (t=3.11, p=0.002), with blacks (M=2.68, SD=1.31) registering more concern than whites (M=2.95, SD=1.32). Figure 2 illustrates these results, with the creation of three groups illustrating the findings. Blacks were less likely to believe that physicians should advise against having children based on genetic tests results than were whites; a substantial number of black and white participants also had relatively unformed attitudes about this issue; and whites were more likely than blacks to believe that physicians should advise patients to avoid having children based on genetic test results. While participants in general did not believe employers should be able to make hiring decisions based on genetic information, differences were observed for employer rights (t(583)=2.27, p<0.05), with blacks (M=1.54, SD=0.85) in less agreement with employer use of genetic information than whites (M=1.72, SD=1.03); education and income did not have significant relationships with views about employer rights. No significant differ-

Table 4. Correlations between Factors

	EMP	CRIM	INS	IND	SOC	GEN
Employer rights (ORG)	1.0	0.13**	-0.23**	0.39**	0.27**	0.24**
Criminal control rights (CRM)		1.0	-0.01	0.10*	0.13*	0.11**
Insurance company rights (INS)			1.0	-0.05	-0.04	0.09*
Individual reproductive rights (IND)				1.0	0.44**	0.21**
Social reproductive rights (SOC)					1.0	0.20**
Genetically based racism (GEN)						1.0

* p<0.05. ** p<0.01.

ences were observed between participants self-identifying as black compared to white for attitudes about insurance company rights or individual reproductive rights. Significant differences in genetically based racism were found ($t(583)=2.88$, $p<0.01$), with blacks ($M=1.86$, $SD=0.94$) holding less polarized beliefs associating abilities with genes and race than do whites ($M=2.09$, $SD=1.02$) after controlling for the significant role of education on these perceptions ($r=-0.10$, $p=0.008$).

DISCUSSION

As the technological spin-offs from the HGP become more prevalent, there are a variety of concerns about the way in which this technology will be incorporated into social life, particularly concerns about genetic discrimination.[42-44] While the work associated with the HGP affirms that social rather than genetic explanations account for disparities in disease linked to race and ethnicity, public messages may lose this in the translation, leaving genetic explanations linked to race uppermost in the public's understanding.[4] The ramifications are far-reaching, as the results of this research revealed that the lay public conceptualizes genetic discrimination as having potential influence in five domains, including individual reproductive rights, social reproductive rights, employer rights, insurance company rights and criminal control rights. Moreover, these perceptions are coupled with racial discrimination in the form of genetically based racism.

There has been little discussion about the reproductive realm associated with genetic discrimination. This is the situation despite the reality that genetic counseling research and practice exhibits a long tradition of awareness associated with women making decisions about having children based in whether they regard themselves to be at "high" versus "low" risk of having a child with genetic anomaly.[45] As genomic healthcare unfolds, an era of counseling for single gene disorders will be displaced by counseling about the multiple genetic contributors associated with disease susceptibility. Moreover, counseling will move from the realm of genetic counselors into primary care practice settings, with physicians and nurses sought out as advisors in this regard. Clearly, the lay public has concerns that knowledge about disease susceptibility associated with genes will spillover into individual and social reproductive health decision-making. Black Americans have historic precedence to set their expectations in this regard, with the criminalization of drug use during pregnancy associated with the identification and detention of more minority women than white women.[46] It follows that a movement toward racializing the prescription of medicine in RBGM may contribute to further erosion of physician–patient relationships and even avoidance of care when care is available.

Perhaps the most attention associated with genetic discrimination in headlines and policy has addressed protecting the rights of citizens in employment situations and with regard to access to health insurance. Only a few years ago, just 11 states addressed genetic findings and the workplace, with North Carolina and Florida protecting black Americans from bias in hiring and insurance practices due to sickle cell test results, Iowa forbidding employers from requiring a genetic test as a condition of employment, and 13 states addressing protection of health insurance.[47] While some progress has been made in this arena, one of the best strategies to escalate protection under the law with regard to HGR is public awareness and understanding.

Finally, expressions associated with a criminal control dimension of genetic discrimination emerged in lay perceptions. This may occur in part as a function of the increasing media entertainment options associated with crime scene investigations and the use of DNA in these scenarios. The concerns about use of this information may also be associated with beliefs that such information may be misused. Blacks and whites differed in their attitudes about discrimination and the social reproduction and criminal control dimensions as well as racial discrimination associated with genetically based racism, findings likely related to the historical and social context of race relations in the United States.

Limitations

As observed in the discussion of the methods and results of this research, a social desirability bias may have contributed to the findings. Participants may have refused to participate in this study due to its focus on assessing levels of racism and perceptions about whether individual characteristics relate to race and genes. Alternatively, individuals who participated may have responded in ways designed to reflect more socially appropriate attitudes. The sensitive nature of efforts associated with gaining insights about public perceptions relating to genes and race guide us to exercise some caution, therefore, in drawing conclusions about the results. The results may be considered all the more important, however, if framed as representative of individuals who may be less polarized in views relating to genetic discrimination and/or genetically based racism than results might have been had individuals with strong racist attitudes or unconcerned about social desirability had participated more frequently. Additionally, we lacked sufficient numbers of Hispanic/Latino or Asian participants to consider possi-

ble differences associated with these racialized social groups. Thus, care should be exercised with regard to generalizing the findings.

Future Applications

The percentage of participants in this research found to believe that race is intrinsically linked to physical, cognitive and social traits suggests that messages which link race, genes and health may be used to legitimize racism. This contributes to the complexities of targeting science-based messages about genetics to the lay public. Racial discrimination is a salient issue already extended to the realm of genetics in the minds of the lay public. Thus, the goal now is responsible communication and message construction that aims to avoid messages that cue or exacerbate racist beliefs.

The tools developed in this research could help message designers avoid the distribution of public communication messages that result in unintended effects, such as intensifying or creating genetically based racist beliefs. For example, the GDI and the GBRI might be used as a screening tool in the formative research phase of a public communication campaign. Message designers might use the instruments as a posttest following exposure to a potential message about HGR. If results reveal that an HGR message triggers higher levels of genetic discrimination and genetic racism as compared to some baseline measure or control group, message designers should then refine the message until its content is found to be less inflammatory. Similar utility may be demonstrated with regard to science curricula associated with genetic health in high-school and college science textbooks. Authors may be cautioned to consider the effects of their renditions of the material on the formation of mindsets inappropriately linking cognitive and other abilities to racial categories.

Physicians who see patients in primary care as well as pharmacists who counsel patients about drug use might also consider the ways that they talk about medications and therapies to insure that the language used reflects attention to the individual in all of his or her characteristics associated with prescribing rather than an arbitrary racial marker. Likely, the age; health status; lifestyle; weight; and behaviors, such as smoking and alcohol consumption, all factor into a physician's prescription, but if a shorthand phrase such as, "Black Americans were found to benefit more from use of this medication for their heart disease," is spoken at the time of making a treatment recommendation, the physician risks not only noncompliance with taking the medication but also a further erosion of trust between caregiver and client.

In sum, messages describing genetic disease may contribute to attitudes that are genetically discriminatory, and messages linking race, genes and health may function to legitimize racism. These potential effects add to the challenge of targeting science-based messages about genetics and health to the lay public. Therefore, any message, however well intended by public health promoters, pharmacogenomic companies and others charged with deriving the public discourse, as well as the interaction between professionals in the healthcare system and their clients, should be considered for its effects on these interlinked attitude sets. In many settings and situations, the tools developed here will permit assessment of such effects early in the planning process and allow the reframing of messages to deflect discriminatory mindsets, thus promoting science-based message design in health communication about genetics.

ACKNOWLEDGEMENTS

The authors acknowledge the contributions of Alan Templeton, Amy Reeder, Paul Achter, Benjamin Bates, Jennifer Bevan, John Lynch, Tasha Dubriwny, Kristan Poirot and Alison Trego to this project.

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