

African-American Males' Knowledge and Attitudes toward Genetic Testing and Willingness to Participate in Genetic Testing: A Pilot Study

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Abstract

This descriptive pilot study explored the knowledge and attitudes of African-American males toward genetic testing and their willingness to participate in genetic testing. A convenience sample of 104 African-American males, from 19 to 79 years of age, was recruited from a national fraternity meeting. Data were collected using four surveys: Demographic and Background Data, Perceived Knowledge of Genetic Testing, Attitudes Toward Genetic Testing, and Willingness to Participate in Genetic Testing. Perceived genetic knowledge was low with a mean score of 5.6; however, participants had a favorable attitude toward genetic testing. Findings from this study suggested that participants were willing to participate in genetic testing with a total score of 46.8. Significant correlations existed between perceived genetic knowledge and willingness to participate in genetic testing. Interventions to increase perceived genetic knowledge and educate the participant on who is conducting the test and how the test will be performed may be beneficial to increase participation in genetic testing.

Key Words: African-American men, genetic testing, genetic testing attitudes, genetic testing knowledge, willingness to participate in genetic testing

Introduction

Prediction of an individual's genetic predisposition for chronic diseases through gene testing holds great promise towards eradicating health disparities. Innovative strategies to improve interventions, to make earlier diagnoses, and to create medications targeted toward specific genetic profiles are vitally important to achieve this goal. All individuals are 99.9% identical in genetic makeup; however, the variation in the 0.1% is significant in identifying diseases and in answering health questions (National Office of Public Health Genomics, 2008). This variation in genetic make-up can specifically be identified as having

a role in significant health discrepancies that exist between African-Americans and other racial/ethnic groups (Jorde & Wooding, 2004). However, it must be noted that a myriad of factors contribute to health inequities distinct from genetics alone.

Background and Significance

The Incidence of Chronic Disease

In health statistics reports, the prevalence of diabetes is approximately 77% higher in African-Americans than in White Americans while strokes are 50% more likely to occur in African-Americans than in White Americans (The Office of Minority Health, 2007; National Diabetes Statistics, 2011). In 2004, African-Americans were twice as likely to die from diabetic-related causes compared to White Americans, and the mortality rates of African-Americans are higher for heart diseases, stroke, cancer, and asthma, as well (The Office of Minority Health, 2007).

The impact of chronic diseases is even worse for African-American men. Remarkably, the life expectancy for African-American males is seven years less than other racial groups with African-American males born in 2004 living 69.5 years compared to 75.7 years for White males born in the same year (Kennard, 2006; Payne, 2007). In the United States, more African-American men develop and have higher mortality rates of prostate cancer than any other racial group. In this population, prostate cancer is second only to lung cancer in causing cancer deaths (The Office of Minority Health, 2007). African-American males are 2.4 times more likely to die from prostate cancer than non-Hispanic Whites but have only a 20% diagnosis rate (The Office of Minority Health, 2007). In addition to these statistics, the Department of Health and Human Services reports that African-American men are 30% more likely to die from heart disease, and twice as likely to die from diabetes compared to White Americans (The Office of Minority Health, 2007).

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African-American Men and Genetic Testing

The participation of African-American men in research and genetic testing is important in finding answers to complex health questions. African-American males, however, do not typically participate in the research to improve patient care regarding drug therapy, treatment of diseases, predisposition to genetic testing, and stem cell and tissue research (Fleck et al., 2001). According to Shavers, Lynch, and Burmeister (2001), knowledge of the Tuskegee experiment resulted in individuals having less trust in medical research and were significantly less willing to participate in medical research.

It is critical to ascertain a baseline level of knowledge in order to determine the areas where more information is needed for purposes of educating and providing health awareness. In addition, in order to improve participation in future genetic research, it is necessary to have an understanding of the population's attitudes regarding genetics and genomics research. It would be helpful to determine the circumstances under which individuals are most willing to participate in genetic testing as well.

Purpose of the Study

The purpose of the present study was to explore the perceived knowledge and attitudes of African-American men toward genetic testing and their willingness to participate in genetic testing. In addition, conditions under which African-American males are most willing to participate in genetic testing are described. The relationships between perceived knowledge, attitudes, and willingness to participate in genetic testing were examined as well. Six research questions were generated and tested in this study and included:

- 1) What is the perceived knowledge of African-American males toward genetic testing?
- 2) What are the favorable attitudes of African-American males toward genetic testing?
- 3) What are the reserved attitudes of African-American males toward genetic testing?
- 4) How willing are African-American males to participate in genetic testing?
- 5) What is the relationship between favorable attitudes of African-American males toward genetic testing and willingness to participate in genetic testing?
- 6) What is the relationship between reserved attitudes of African-American males toward genetic testing and willingness to participate in genetic testing?

Methodology

Research Design, Sample and Setting

This was a descriptive pilot study that was undertaken to explore the knowledge and attitudes of African-American males toward genetic testing and their willingness to participate in genetic testing. A convenience sample of 104 ($N = 104$) African-American males, from 19 to 79 years

of age, was recruited at the district meeting of a national African-American fraternity. The district consists of approximately 477 members from fraternity chapters in two Midwestern states. The fraternity members join at either a graduate or undergraduate level. All graduate level candidates must have a minimum of a bachelor's degree from an accredited university to be eligible for membership into the fraternity. Undergraduate candidates must be enrolled in a four-year accredited college, possess a cumulative 2.5 grade point average (in a 4.0 system), and have completed at least 36 semester hours (National Fraternity, 2007). The eligibility criteria were: self-identified African-American or Black males, at least 18 years of age and able to read English.

To establish trusting relations and therefore increase participation, several factors were taken into account. The respondents participated by completing an anonymous survey. One of the researchers, an African-American, answered all questions regarding the research study and described all provisions made to protect the participants (Shavers et al., 2001).

Protection of Human Subjects

This study was approved by the Institutional Review Board (IRB) and permission was received from the local African-American fraternity officers and District Representative to recruit research participants at the district meeting. A waiver of written consent was granted by the IRB.

Instrumentation

Demographic and Background Data Instrument. A Demographic and Background Data Instrument that included nine items that assessed age, educational level, genetically linked chronic disorders diagnosed in self or others, previous genetic testing, and genetic education/training was administered. In addition, 15 true or false structured items taken from the Factual Genetic Knowledge Questionnaire developed by Morren, Rijken, Baanders, and Bensing (2007) and Calsbeek, Morren, Bensing, and Rijken (2007) were used to assess factual genetic knowledge. These factual genetic knowledge items evaluated knowledge about the association of genes and diseases and the association of genes, chromosomes, cells, and the body. Sample items included: "A gene is a disease." "A gene is a cell." Correct answers were scored as 1 and incorrect/don't know answers were scored as 0. The total score for the factual genetic knowledge items ranged from 7 to 15.

At the end of the survey, two open-ended questions were included. These questions allowed the participants to include comments on likeliness to participate in genetic testing and willingness to participate.

Perceived Knowledge of Genetic Testing Scale. The Perceived Knowledge of Genetic Testing Scale, developed by Morren et al. (2007) and Calsbeek et al. (2007), was used to assess the possibilities and consequences of DNA testing. The instrument has two subscales: medical possibilities of genetic testing, which consists of five items, and social

consequences of genetic testing, which consists of six items. A 3-point scale is used to determine knowledge (0 = nothing, 1 = I know a little, 2 = sufficient knowledge). Total perceived genetic knowledge is calculated by a mean score of the total scale with a range of 0 to 21 (Cronbach's alpha 0.91) (Calsbeek et al., 2007). Subscale mean total scores are also calculated: perceived medical knowledge (range 0-10) and perceived social knowledge (range 0-12). The reliability for both scales was 0.88 and 0.86, respectively (Calsbeek et al., 2007). In the current study, the total perceived genetic knowledge Cronbach's alpha reliability coefficient was 0.91. The perceived social knowledge subscale Cronbach's alpha was 0.88 and 0.85 for the perceived medical knowledge subscale.

Attitudes Toward Genetic Testing Questionnaire. The Attitudes Toward Genetic Testing Questionnaire was developed by Morren et al. (2007) and was further refined by Calsbeek et al. (2007). Responses to the 13 items yielded two scores: one for favorable attitudes and one for reserved attitudes. No total score for this instrument exists. The items are scored on a 5-point scale (1 = strongly disagree; 2 = disagree; 3 = don't know/no opinion; 4 = agree; 5 = strongly agree). Scores for the favorable attitudes subscale (6 items) ranged from 6 to 30, and scores for the reserved attitudes subscale (7 items) ranged from 10 to 35. The favorable attitudes subscale has a Cronbach's alpha reliability of 0.82 and the reserved attitudes subscale has a Cronbach's alpha reliability of 0.70 (Calsbeek et al., 2007). In the current study, the Cronbach's alpha reliability coefficient for favorable attitudes was 0.93 and for reserved attitudes was 0.72.

Willingness to Participate in Genetic Testing Instrument. Willingness to participate in genetic testing was operationally defined as the mean total score on the Likelihood of Participation scale (LOP), a subscale from the Tuskegee Legacy Project (TLP) Questionnaire designed by Kegeles (Katz et al., 2006). The mean was calculated from the scores for the items related to one question on willingness to participate at the present time, seven items related to willingness to participate based on who is conducting the test, and nine items related to willingness to participate based on what the participant is asked to do. The LOP scale is a validated 17-item scale measuring a minority persons' willingness to participate in biomedical research and the reasons for the decisions. For the current study, the scale was modified to ask about genetic testing with permission from the author. On the scale, the words "medical research" were changed to "genetic testing." The items are scored on a 6-point scale (0 = refused, 1 = very unlikely, 2 = somewhat unlikely, 3 = not quite sure, 4 = somewhat likely, 5 = very likely). A refusal category was added to the Likert scale to determine the number of individuals that would refuse a particular item. The total scores range from 0 (least willing to participate) to 85 (most willing to participate). Katz and colleagues (2007) reported that the LOP domain met the psychometric standards for scales. In this study the Cronbach's alpha coefficient was 0.91.

Procedures

In recruitment of potential study participants, announcements about the study were made by fraternity members at breakout sessions held at the district meeting. When potential participants came to the booth, information about the research study was provided. Eligibility criteria were clearly displayed. Potential participants were informed that extra measures would be taken to ensure their confidentiality. No names or other identifiers were included on the questionnaires and the study was completely anonymous. Packets including a cover sheet and all questionnaires were provided to the fraternity member in an envelope for them to complete in a private area. After the participants' completion of the survey, the researcher examined the surveys for the presence of missing data. Participants were then given a raffle ticket to participate in a raffle held during the district meeting with the opportunity to win a \$25 gas card.

Statistical Analysis

Version 17 of the SPSS statistical software was used to analyze data. Descriptive statistics were used to evaluate data related to demographics, knowledge, attitudes, and the willingness to participate. A Pearson Product Moment Correlation was used to determine if relationships existed among the variables. The alpha was set at a 0.05 level (two tailed) to determine these significances.

Results

One hundred and four surveys ($N = 104$) that were distributed were completed at the District meeting. No surveys returned had more than 10% of the data missing on any of the instruments.

Sample Characteristics

The mean age of this sample was 40.3 ($SD \pm 14.2$) years. Ages ranged from 19 to 79 years. Fifty-one of the participants (49%) had a 4-year college degree and 32 participants (30%) possessed a master's or doctoral level degree. While 12 of the participants (11.5%) reported having had genetics training or education, 92 of the participants (88.5%) had never had genetics training or any form of genetics education. Only 1 participant out of 104 had undergone genetic testing and only 8 participants had a relative or friend who had undergone genetic testing. Sample characteristics are presented in Table 1 (see Table 1).

Chronic diseases were common in this sample of African-American men. Forty-five (43.3%) of the participants had diagnoses of one or more chronic diseases, while 59 (56.7%) had no history of chronic disease. Hypertension was the most prevalent, with 17 (37.8%) reporting this diagnosis; however, 13 (28.9%) of the participants were diagnosed with multiple chronic disorders. In the majority of participants with multiple chronic disorders, hypertension was one of the co-morbidities. The chronic disease categorization is presented in Table 2 (see Table 2).

Table 1. Sample Characteristics (N = 104)

Sample Characteristics	n (%)
Educational level	
High school or GED	17 (16.3)
Trade school, associate degree or some college	4 (3.8)
4 year college degree	51 (49.0)
Master's degree	29 (27.9)
Doctoral degree	3 (2.9)
Genetic education/training (%)	
Yes	12 (11.5)
No	92 (88.5)
Genetic testing (%)	
Yes	1 (1.0)
No	103 (99.0)
Friend or family member with genetic testing (%)	
Yes	8 (7.8)
No	95 (92.2)
Chronic disease	
Yes	45 (43.3)
No	59 (56.7)

Table 2. Participants' Chronic Disease Categorization (N = 45)

Chronic Disease	n (%)
Cancer	1 (2.2)
Prostate	3 (2.9)
Pancreatic	1 (1.0)
Depression	1 (2.2)
Heart problems	1 (2.2)
Diabetes mellitus	3 (6.7)
Sickle cell/Sickle cell trait	3 (6.7)
Asthma	6 (13.3)
Multiple chronic illnesses	13 (28.9)
Hypertension/High blood pressure	17 (37.8)

The mean score for factual genetic knowledge was 11.5 (76.7%). Participants had the most knowledge about the association between genes and disease. This is exemplified by the statement, "All serious diseases are hereditary." This statement was answered correctly by 98.1% of the participants. On the other hand, the participants knew little about statements related to genes and the body. This is best exemplified by the statement, "Different body parts include different genes." This statement was answered correctly by only 40% of the participants.

Perceived Knowledge of Genetic Testing

The mean total perceived genetic testing knowledge was 5.6 ($SD \pm 4.8$) on a scale of 0 to 21. The perceived medical knowledge score mean was 3.2 ($SD \pm 2.37$) on a scale of 0 to 10. Also, the perceived social knowledge score mean was 2.4 ($SD \pm 2.85$) on a scale of 0 to 12. The highest percentages of those reporting no knowledge were evident in the items related to social consequences of genetic testing. The least known of all statements was related to the consequences of genetic testing for work (75%, $n = 78$). However, the participants perceived to have more sufficient knowledge about medical consequences of genetic testing. The most sufficient knowledge of all statements was related to the likelihood of early detection of certain disorders through the use of genetic testing (32.7%, $n = 34$).

Attitudes, Favorable and Reserved, of African-American Males

In assessing the favorable attitudes toward genetic testing, six statements were examined. For the favorable attitude statements, the mean total score was 25.0 ($SD \pm 5.2$) on a scale of 6 to 30. Participants favored the item regarding knowledge of whether their disease is hereditary the most. Fifty-four (51.9%) participants strongly agreed with this item. Participants least favored the item related to informing their children of genetic test results. Two (1.9%) participants strongly disagreed with this item.

Reserved attitudes were assessed using seven statements. The total mean was 20.0 ($SD \pm 4.9$) on a scale of 7 to 35. The means of the seven statements ranged from 2.3 ($SD \pm 1.0$) to 3.8 ($SD \pm 1.1$). Participants were most reserved about the likelihood of genetic testing changing the future. The mean for this item was 3.8 ($SD \pm 1.1$) with approximately 65% of the participants agreeing or strongly agreeing to this statement. In comparison, less than 10% ($n = 10$) of the participants agreed or strongly agreed with the statement regarding the idea that a genetic test is frightening. The mean for the statement regarding genetic testing as frightening was 2.3 ($SD \pm 1.0$).

Willingness to Participate in Genetic Testing

Willingness to participate in genetic testing had a mean of 46.8 ($SD \pm 15.3$) on a scale of 0 to 85. The item "willingness to participate in genetic testing at the present time" had a mean of 3.17 ($SD \pm 1.4$). However, this mean changed when the participant was told specifically who was conducting the test or what action must be performed. The mean score for the seven items related to willingness to participate based on who was conducting the genetic testing was 16.3 ($SD \pm 7.3$). The mean score for the nine items related to willingness to participate based on what the participant was asked to do was 27.6 ($SD \pm 9.0$).

The results of the willingness to participate scale were further analyzed. Only 39 (40.7%) participants were somewhat likely or very likely to participate at the present time in genetic testing. However, more than 75% of participants were somewhat likely or very likely to participate if the

genetic testing was performed by their physician ($n = 79$) or if they only had to do exercises ($n = 79$). Furthermore, under various circumstances, participants had a higher percentage of completely refusing genetic testing. More than 25% of the participants would refuse genetic testing if the testing was conducted by a tobacco company ($n = 39$), a drug company ($n = 30$), or an insurance company ($n = 30$). Also, greater than 20% would refuse genetic testing if the testing was conducted by minor ($n = 23$) or major surgery ($n = 26$).

Significant Relationships

A significant, but modest, correlation existed between total perceived genetic knowledge and willingness to participate, depending on what the participant was asked to do ($r = 0.22, p = 0.23$). Specifically, medically perceived genetic knowledge was significantly correlated to willingness to participate ($r = 0.21, p = 0.03$). No correlation was found between favorable attitudes and willingness to participate in genetic testing ($r = 0.08, p = .45$). Also, no correlation was found between reserved attitudes and willingness to participate in genetic testing ($r = -0.16, p = 0.12$).

Additional Information

In addition to the quantitative results, participants were asked two open-ended questions related to willingness to participate specifically in genetic testing. Forty-four participants provided comments on likelihood to participate in genetic testing and 23 participants provided additional comments on willingness to participate. Three main responses were identified from the comments: information protection, researcher credibility, and distrust for medical research and genetic testing. Comments included: "The sponsor and tester's reputation and credibility will have a lot to do with the willingness to participate," "I do not trust most open systems," and "To participate in genetic testing my data must be protected at all costs."

Discussion

In this descriptive study, data were collected from a convenience sample of 104 African-American males at a national fraternity district meeting in a Midwestern state. Participants were all African-American males between the ages of 19 and 79 years who spoke English. Greater than 75% ($n = 83$) of the participants had a 4-year college degree or higher. The factual genetic knowledge score was 77%; however the perceived genetic knowledge score was 27%. The favorable attitudes mean score was 25.0 ($SD \pm 5.2$) and the reserved attitudes mean score was 20.0 ($SD \pm 4.9$). The mean willingness to participate in genetic testing score was 46.8 ($SD \pm 15.3$). No correlation existed between favorable or reserved attitudes and willingness to participate in genetic testing. However, there were significant correlations between perceived genetic knowledge and willingness to participate in genetic testing.

The factual genetic knowledge of the sample was high when compared to previous studies (Calsbeek et al., 2007). The mean factual genetic knowledge score was

11.5 ($SD \pm 1.7$) for 15 items. In comparison to the Calsbeek et al. (2007) study, the percentage of respondents with a correct answer on the factual knowledge items in this study was higher. The correct factual knowledge items in the current study ranged from 40.4% for the item about makeup of body parts to 98.1% for the item related to seriousness of genetic diseases. In the study conducted by Calsbeek et al. (2007), the mean was 9.0 ($SD \pm 4$). The reference group in the study by Calsbeek et al. (2007) had a sample size of 181 and the percentage of respondents with a correct answer on all 16 items ranged from 12% to 87%.

The total perceived knowledge mean was low at 5.6 ($SD \pm 4.8$) but was comparable to Calsbeek et al. (2007) where a sample of participants with asthma had a total perceived knowledge mean of 5.4 ($SD \pm 4.3$). The perceived medical knowledge score mean was 3.2 ($SD \pm 2.37$); this is consistent with the score mean of 3.1 ($SD \pm 2.3$) reported by Calsbeek et al. (2007). The mean perceived social knowledge score was 2.4 ($SD \pm 2.85$). This mean was higher than the 1.8 ($SD \pm 2.4$) found by Calsbeek et al. (2007). As reported by Morren et al. (2007) and Calsbeek et al. (2007), the total perceived knowledge was low and most participants reported to have no knowledge on perceived social knowledge.

The mean score for the favorable attitudes was 25.0 on a scale of 6 to 30. Participants in previous research had mean scores that ranged from 22.8 to 24.4 on a scale of 6 to 30 (Calsbeek et al., 2007). Similar to previous research, the majority (70 - 80%) of participants who responded had favorable attitudes about using the DNA-testing for disease detection and DNA research is hopeful for disease treatment (Morren et al., 2007). The mean total reserved attitudes score was 20.0 on a scale of 7 to 35. In previous research, the mean total score on reserved attitudes ranged from 20.1 to 22.1 on a scale of 7 to 35 (Calsbeek et al., 2007). Similar to previous research, the highest percentage of respondents agreed with the statement that the likeliness of a DNA-test would affect one's future (Morren et al., 2007).

Willingness to participate mean total score was 46.8 ($SD \pm 15.3$) on a scale of 0 to 85. In this study, African-American males were willing to participate in genetic testing; however, who is conducting the testing and what they have to perform during testing affects their willingness. The majority of the participants ($n = 79, 76.7%$) were more willing to have genetic testing if it was conducted by their medical physician. This is consistent with previous research that indicated that men are more willing to participate in genetic research (> 40%) if the research is conducted by their own physician (Katz et al., 2006). Culler et al. (2002) found that a physician's recommendation positively influenced interest in genetic testing.

Similar to previous research findings, various factors are involved in determining if a person will participate in genetic testing. One of the factors involved in this was who conducted the genetic testing (Katz et al., 2007). More than 25% of the participants would refuse genetic testing if a tobacco company, a drug company, or an insurance

company conducted the testing. Previous researchers have shown that less than 25% of African-Americans would participate in medical research if the government, a tobacco company, a drug company, or an insurance company conducted the testing (Katz et al.).

Limitations of the Study

The generalizability of the study was limited by several factors. First, the study was a convenience sample of participants recruited at a national fraternity district meeting. Secondly, this study is specific to African-American men. Lastly, due to the higher level of education of these fraternity members, the participants may have been more willing to complete the research survey, to have attitudes that were more favorable toward genetic testing, and to have an overall increase in willingness to participate in genetic testing.

Implications for Practice

The results of this research study yield important implications for health provider education. The findings increase awareness about factual and perceived knowledge regarding genetic testing, attitudes toward genetic testing, and information about willingness to participate in genetic testing in an African-American male sample. Introduction of this information into curricula may help increase awareness of health providers about this topic and also improve education to patients diagnosed with chronic diseases that have genetic linkages. In addition, information is provided about the circumstances in which African-American males are most likely to participate in genetic testing. These circumstances can assist health-care providers in improving recruitment efforts for medical research and genetic testing. In addition, these findings could be included in courses related to patient care and research methods.

The knowledge and attitudes toward genetic testing and willingness to participate in genetic testing have implications for practice. A first step is to recognize that the African-American male sample perceived that they possessed little to no knowledge about genetic testing although they scored high on factual knowledge. Interventions may be implemented into practice to increase both the factual and perceived knowledge of African-American males. In turn, this may increase participation in genetic testing. In addition, awareness of the attitudes of African-American males toward genetic testing may ensure that the most recent genetic information is provided to patients and their families.

In our multicultural society, populations such as African-American males possess varying attitudes regarding the health-care system and genetics. It is crucial that culturally competent providers are aware of these attitudes and what is known about genetics to ensure that current genetic-based education may be provided to patients and their relatives; and training programs may be created to provide the best care possible to clients. It is important that providers are aware of cutting-edge information regard-

ing genetics and genetic testing to ensure that evidence-based genetics research findings may be implemented into practice. Health-care providers must understand the willingness or unwillingness of African-American males to participate in genetic testing. Awareness of the conditions that African-American males are most likely to participate can possibly aid in the design of research studies and genetic counseling related to genetic testing. In addition, the findings from this study may be used to assist in discussions related to public policy changes directly affecting African-American males and genetic testing. To garner willingness to participate in genetic screening, it may be necessary to make modifications related to conducting cancer screenings and genetic education, and to how assessments of the needs of the African-American male population are made. In addition, findings from this and other studies can be used to develop indicators for collaboration for genetic testing in the African-American community, thereby assuring more compliance with such needed testing.

Implications for Future Research

Several recommendations exist for future research. The results of this research study suggest that a discrepancy exists in the factual and perceived knowledge of African-American males. Replication of this study needs to occur with variation. Additional studies need to have a large national random sample so that all results can be generalized. In addition, follow up studies may be conducted examining a more heterogeneous sample of African-American men, such as variations in socioeconomic and educational levels. The study could also be conducted comparing males of different races and ethnic groups, along with having different ages and educational backgrounds.

Conclusions

Information about African-American males' knowledge of genetic testing and willingness to participate in genetic testing will assist providers in planning patient education programs about genetic testing. Interventions to educate participants on the specifics of genetic testing such as who is conducting the genetic testing and how the test will be performed may prove beneficial in increasing participants' willingness to have genetic testing. Furthermore, the results of this study may be used to guide faculty in developing genetic-related programs for students.

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