In the News

Minority Research: Building Trust Project Aims to Improve Participation and Strengthen Capacity for Investigators and IRBs
Terry Hartnett

Electronic Health Record Integration: Changing the Game for Clinical Research
Sue Coons, MA

Ethical Review of Best Practices for Pediatric Cellular/Gene Therapy Clinical Trials
Anna J. DeMarinis, MA, CQA(ASQ), MTA(ASCP)SBB

Continuing Education

Regulatory Update
Minority populations in the United States historically have been under-represented in all aspects of research — clinical trials for new drugs, devices and biologics, social science, public health, and health services research. The general assumption by many is that African Americans in particular, as well as Hispanics, Native Americans and Asians, do not trust the research process based on past history of abuse such as the United States Public Health Service Study of Syphilis in Tuskegee, AL.

However, there are other factors that lead to low minority participation, including a lack of access (insurance, transportation, geography) to health care overall, exclusion criteria, low literacy, and language differences. Of critical importance is the number of minority researchers who are interested in studying diseases and the impact of disease on people of different races and ethnic backgrounds. Racial and ethnic minorities make up 25% of the U.S. population but comprised only 13.8% of funded principal investigators on NIH research and program grants in fiscal year 2002.

It is important for all research professionals to understand the reasons behind the low participation of both participants and researcher professionals in the area of minority research. Perhaps most importantly is focusing on ways to encourage more minority participation because of the impact on the scientific integrity of research overall as well as the public health of all U.S. citizens. “As a general rule, scientists are passionate about their research,” says Robert Tai, a principal investigator in a long-term study on why minorities are under-represented in research. “This passion is often drawn from their own personal experience, as it is with all of us,” he says. “As a result, many biomedical researchers choose to study the disease that they have some personal connection to. A lack of diversity in the biomedical research corps may also mean that many diseases facing segments of the U.S. population who are not represented will not be studied as extensively.”

This lack of diversity among research investigators adds to the already alarming disparities in health care for minority populations. For example:

- African Americans are less likely than whites to survive 5 years after being diagnosed with most forms of cancer at any stage of diagnosis.
- Nearly a quarter (23%) of Hispanic women have never had a Pap smear.
- African American men and women have a 17% higher rate of colon cancer than their white counterparts.
- Hispanic men and women have double the cancer rate for liver cancer and higher mortality.
The goal of this article is four-fold:

1. To explain the historical reasons, as well as current factors, that impact the participation of minorities in research — both as study subjects and as investigators.
2. To highlight disparities in health care for minority populations and how a lack of addressing these disparities through research poses significant public health problems.
3. To outline the results of a nationwide survey of minority populations on attitudes and beliefs about research.
4. To outline the core curriculum for an educational program on research for communities as well as the core curriculum for an educational program on minority participation for research.

- Mexican American adults are more than twice as likely as non-Hispanic white counterparts to be diagnosed with diabetes and 1.5 times more likely to develop end-stage renal disease.3

"We need to focus on how to better understand and remedy these issues in public health and research," says Sandra Crouse Quinn, associate dean for public health initiatives and senior associate director, Center for Health Equity, University of Maryland School of Public Health, College Park, MD. "The issue is complex and requires a comprehensive approach. So far, we have only taken a look at pieces of the problem." Quinn says institutional commitment is essential to improving minority participation. She is a co-principal investigator on a Bioethics Research Initiative grant for a pilot program called Building Trust between Minorities and Researchers. Funded by a grant from the National Center for Minority Health, the project has two phases. The first was a national telephone survey of African Americans and Latinos on attitudes toward research participation that was conducted from June to December 2010. The second phase is the development of a curriculum designed for communities about research coupled with a curriculum for research professionals.

"The survey results show us that despite common perceptions, minorities are, in fact, willing to participate in research studies including those that involve invasive procedures," says Stephen B. Thomas, director of the Center for Health Equity, School of Public Health, University of Maryland, and co-investigator for Building Trust. "The results are encouraging and also show us that we have room to improve," he says. That is what the curriculums for both communities and for researchers aim to do.

Previous projects have looked at the role of minorities in clinical trials. The Elimination of Disparities in Clinical Trials Project (EDICT) focuses on policy and research and addresses the health policy and patient advocacy that affects recruitment of targeted populations.4 A field research demonstration examines the barriers and aids to recruitment and retention in order to develop recruitment materials. "The key for researchers is to develop the appropriate participation that you want based on what you are studying," says Armin Weinberg, principal investigator for EDICT. "It's not a matter of quotas or convenience populations."

Building Trust, says Thomas, includes information honed from the EDICT project and others but takes a definitive step beyond with its focus on an educational program for research professionals. "To the best of our knowledge there is nothing else out there like Building Trust," he says.

Why Are Minorities Under-represented in Research?

There is no doubt that the reputation of research in the United States is permanently scarred by the facts of the U.S. Public Health Services (USPHS) syphilis study. Researchers who have studied the legacy of Tuskegee say that it is important to remind both research professionals and potential participants what took place in that trial. "What worries me the most is when the Tuskegee study is forgotten," writes James H. Jones in the Foreword to Tuskegee Truths: Rethinking the Tuskegee Syphilis Study.5 "What has impressed me the most about the Tuskegee study is its staying power as a subject of public concern," he writes. "We know that knowledge about the study circulates continually among many members of the African American community. The presidential apology (President Clinton), the film Miss Evers' Boys, the revelations of other kinds of research that trampled on the rights of subjects, and the continued teaching of the scholarship on the study all help to introduce differing understandings to broader and broader members of the public and research communities," says Jones.

In his history of Tuskegee titled, Bad Blood, Jones says he "sought to learn how racial attitudes affected the perception of disease that white physicians brought to their African American patients, and having done so, I wanted to learn how those attitudes altered the way in which white physicians responded to disease in the black community."6

Here, briefly, are the facts about the USPHS Syphilis Study that every research professional should know. The study was conducted by the USPHS in rural Macon County, Alabama, (in and around the county seat of Tuskegee) among men with untreated syphilis for 40 years (1932–1972). Two
hundred ninety-nine men who had syphilis and 201 who were free of the disease served as controls. There was no formal protocol. The basic procedures called for periodic blood testing and routine autopsies to supplement the information that was obtained through clinical examinations. The fact that only men who had late, so-called tertiary syphilis were selected for the study indicated that the investigators were eager to learn more about the serious complications that result during the final phase of the disease,” writes Jones.

Although there is no written document that records the conversations, it is generally agreed that the men were told that they “had bad blood.” However, there is no indication that the subjects had any idea of what that term meant. “Dr. JW Williams, who was serving his internship at Andrews Hospital at the Tuskegee Institute in 1932 and assisted in the experiment’s clinical work, stated that neither the interns nor the subjects knew what the study involved. ‘The people who came in were not told what was being done. We told them we wanted to test them. The subjects thought they were being treated for rheumatism or bad stomachs,” Jones says. The subjects actually received no medical treatment at all.

In 1940, penicillin was developed, but the USPHS study of syphilis continued and the men were never given the antibiotic. There were also available treatments in 1932, but the mercury and two arsenic compounds were highly toxic. A Centers for Disease Control (CDC) official said that these drugs offered “more potential harm for the patient than potential benefits.” The Tuskegee Institute also claimed that it had lost contact with earlier subjects in the study in 1940.

It is easy to see how this history would lead to mistrust about research in the African American community and other vulnerable populations. The critical element then, to improving participation, is to rebuild that trust. “African Americans know what happened in the Tuskegee trials and they also understand that the government has implemented many safeguards to prevent this from happening again. But some also have their own present-day experience(s) with the medical community that are not positive,” says Quinn.

“The fine line is respect,” says Felicia Savage, a health coach and faculty research assistant for the Healthy Black Family (HBF) program in Pittsburgh, PA. Thomas founded the Healthy Black Family program, which served as the pilot site for the Building Trust community curriculum earlier this year. Savage co-facilitated the pilot. “It became clear in our community meetings that the reasons why minorities do not trust researchers is Tuskegee but also their own perceived experience with racism in health settings today,” says Savage.

Quinn says more institutional commitment to minority communities is needed. “It is not as simple as hiring an African American or Latino recruiter,” she says. Quinn is currently working on a review of data about minority recruitment and retention and says it breaks down into two clusters: one recruitment strategy is basically word of mouth, doctor referral, and financial incentives. A second approach adds community advisory boards, community partnerships (like HBF), racial and ethnic media, and field sites in the local communities. One of the primary reasons this second approach is more successful in minority recruitment is that it addresses the issue of access, says Quinn. “Community partnerships show a long-term investment, a concrete example of the health care institution’s interest in giving back to the community. They can include simple events such as health fairs and basic health screenings,” she says. Many minorities access their health care in places where research is not conducted (e.g., the emergency room), and many providers to minority communities (particularly low-income communities) are not asking patients to participate in clinical trials because they have no direct access to research institutions. Researchers need to reach out to these providers.

Although minority attitudes about research can and should be improved with community commitment and education, it is simplistic to view the participants as the sole barrier that must be addressed. Tai’s study, called Transitions in the Education of Minorities Underrepresented in Research (Project TREMUR), is being conducted at the University of Virginia, Charlottesville, VA, where Tai is a professor of education, and at the Washington University of St. Louis School of Medicine. The study is funded by a $1.275 million grant from the National Institute of General Medical Sciences (NIGMS) of the National Institutes of Health (NIH).
TREMUR began in 2010 and will run for five years. It will study what accounts for the educational choices made by minorities that are under-represented in research, why individuals choose to become scientists, how and why they make the professional choices that lead them to become independent researchers, and why some leave the field at various stages, says Tai.

Several previous studies have looked at the experiences of researchers and barriers that kept them from doing research in minority communities, and some academic medical centers have offered research grants to assist minority researchers through funding from the NIGMS.

In 2005, a mapping project (a mixed-methods planning approach that integrates common data collection processes with multivariate statistical analyses) that generated a series of “concept maps” was used for data interpretation and as the core of a meeting with minority investigators and investigators at minority institutions. The authors identified nine barriers to minority investigator competition for NIH funding. They are:

1. Inadequate research infrastructure, training, and development
2. Barriers to development as independent researchers
3. Inadequate mentoring
4. Insensitivity, misperceptions, and miscommunication about the specific needs of investigators involved in research with minority communities
5. Institutional bias in NIH policies
6. Unfair competitive environment
7. Lack of institutional support
8. Lack of support for research topics/methods relevant to research with minority communities
9. Social, cultural, and environmental barriers

They also identified eight general themes as actions that NIH might take to reduce barriers, rated in priority. At the top of the list was creating opportunities for mentorship and collaboration. Second, they recommended an increased commitment and accountability of institutions funded by NIH as well as NIH. Other ideas included sensitizing and diversifying the grants program, providing more technical assistance for grant review and skill-building programs, increasing funding for career development, cultivating long-term relationships between NIH and its constituencies, broadening the scope and type of funding, and facilitating professional and organizational development.

**Disparities and Lack of Research Participation Affect Public Health**

For many years women and children did not participate in clinical trials, and therapy was based on clinical trial results produced solely in men. Just as there are differential effects of drugs on women vs. men and adults vs. children, there can be differential effects in African Americans, Latinos, Asians, Native Americans, and Caucasians. We don’t know if these effects are happening because so few minorities are study subjects.

The National Cancer Institute’s Prostate Cancer Prevention Trial (PCPT), for example, recruited 18,882 men. Only 4% were African American, and another 4% were other minorities. However, African American men are 1.3 times more likely to develop prostate cancer than their white counterparts. In addition, this trial also included a specific outreach to address minority recruitment. Minority recruitment was emphasized through the study manual and training that occurred at trial activation. Supplemental minority recruitment activities were initiated a year later after study activation and continued through the end of accrual period. Minority recruitment was emphasized in training seminars, distribution of specific materials, engagement of four consultants for minority recruitment, production of a minority recruitment manual, and a small pilot study involving minority outreach recruiters, according to the study. The researchers concluded that the timing of recruitment strategies may have played a role in the poor outcomes. “We suggest that a long-term perspective is required for successful recruitment of minority participants in clinical trials. Likewise, extensive minority recruitment efforts must be ready to implement at trial activation.”

Another prostate cancer trial demonstrated that the study design/exclusion criteria may limit minority participation but also successfully developed and implemented innovative and comprehensive recruitment strategies that resulted in higher minority enrollment. The Selenium and Vitamin E Cancer Prevention Trial (SELECT) sought to determine if dietary supplements could reduce the risk of prostate cancer in high-risk patients such as African American men. But men with uncontrolled hypertension were excluded. The SELECT study set a goal of 24% for minorities (20% African American, 3% Hispanic, and 1% Asian) and met that goal. SELECT used five basic recruitment strategies. They included:
• Minority recruitment during site selection
• Expanded eligibility criteria that included lowering the age for African American men and men with controlled comorbid illnesses
• A national infrastructure (a large number of clinical centers across the country)
• Additional funding to sites with the potential to increase African American enrollment
• Additional media opportunities to promote SELECT

"Some of the communities that are at most risk for higher incidence for prostate cancer also have a higher prevalence of hypertension," says Claudia Baguet, professor of medicine at the University of Maryland School of Medicine, Baltimore, MD. "Other conditions that may preclude people from participating in trials include diabetes, peripheral arterial disease, and chronic pulmonary disease."

There is a plethora of data showing that the impact of disease states — and even morbidity and mortality — is dramatically different among all of these groups. "We can't practice evidence-based medicine if we don't have research on populations that are impacted," says Weinberg, who is now chief executive officer of Life Beyond Cancer. Disparities in the numbers of minorities in research raise the question of both scientific integrity and ethical research.

Quinn also found in her public health work beginning in the 1990s, and most recently regarding the H1N1 influenza pandemic, that racial and ethnic disparities could potentially have a devastating impact on public health in the United States.

"We conducted a nationally representative survey among a sample drawn from more than 60,000 U.S. households," says Quinn. "We asked respondents about their ability to impose social distance in response to public health recommendations, their chronic health condition, and their access to health care," she says. "We were concerned about the willingness and ability of minorities to stay home from work during a pandemic and to take emergency use drugs." In a separate study, Quinn and her colleagues asked minorities about their willingness to take an unapproved vaccine or emergency use drug.

As of October 2009, the CDC had recorded widespread H1N1 influenza activity in 46 states. There were also increasing reports of racial/ethnic disparities in H1N1 complications and hospitalization rates. Quinn's research found that African Americans had the highest susceptibility to the virus. When it came to willingness to take a vaccine, race was significantly associated with refusal to take the vaccine (66.5% of whites and 60% of blacks compared to 47.4% of Hispanics would refuse the vaccine). Race also was significantly related to the decision to take a drug; 65% of Hispanics said they would agree to take the drug, 54.6% of whites, and only 46.5% of blacks.

Building Trust Survey Results

Although there is no doubt that there is some level of mistrust of research and taking unproven drugs and vaccines even during a pandemic, the survey done by the Building Trust project showed that the door was definitely open to improving trust and research participation. Thomas explains that the project overall has three objectives:

- Increase the participation of African Americans, Hispanics, and other minority populations in public health and biomedical research, including clinical trials
- Strengthen the capacity of investigators, institutional review board members, and other research personnel to work effectively with minority communities
- Create a sustainable infrastructure of training and educational initiatives

The first step in accomplishing these goals, say Thomas and Quinn, was to determine the baseline attitudes of minorities about research participation. A national telephone survey was conducted over a 6-month period last year. Urban areas were oversampled to reach the target population. It was conducted in both English and Spanish and responses were strictly anonymous. Overall 2,455 people agreed to participate: 1,264 Latinos and 1,191 African Americans. Other demographic data: 34.7% male, 65.3% women; 9.9% between 18-24 years old, 23.4% were 65 or older; 54% had obtained a bachelor's degree; 39.6% were married; 34% were working full time; 26.2% were retired; 77.9% had health insurance; and 55.9% made less than $36,000 a year.

"The survey found that there is a high willingness among both African Americans and Latinos to do a number of research-related activities," says Thomas. More than 80% of both groups said they would take a survey, participate in an educational program, and do exercises; more than 70% of both said they would participate in a group interview, limit or restrict their diet, give blood, give urine, or take a DNA test. More than 50% said they would take medicine by mouth. Between 39-40% said they would take a new drug as
Figure 1. Does knowing that there are federal rules, review boards, and community members of boards make you very likely, somewhat likely, or not likely at all to participate in a medical research study?

<table>
<thead>
<tr>
<th>Likelihood</th>
<th>African Americans (n = 1168)</th>
<th>Latinos (n = 1255)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very likely</td>
<td>50%</td>
<td>52%</td>
</tr>
<tr>
<td>Somewhat likely</td>
<td>21%</td>
<td>20%</td>
</tr>
<tr>
<td>Less likely</td>
<td>10%</td>
<td>8%</td>
</tr>
<tr>
<td>Not at all likely</td>
<td>20%</td>
<td>18%</td>
</tr>
</tbody>
</table>

Figure 2. Because people like you can serve on review boards, how confident do you feel about participating in research?

<table>
<thead>
<tr>
<th>Confidence</th>
<th>African Americans (n = 1168)</th>
<th>Latinos (n = 1255)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very confident</td>
<td>55%</td>
<td>60%</td>
</tr>
<tr>
<td>Somewhat confident</td>
<td>20%</td>
<td>20%</td>
</tr>
<tr>
<td>Not confident at all</td>
<td>20%</td>
<td>18%</td>
</tr>
</tbody>
</table>

Community Education

Answers to these questions served as the basis for the educational curriculum. “The primary goal of this education is informed decisionmaking. It is possible that the person will still say ‘no’ to participating in a trial but we hope that is an informed choice,” Thomas adds. The curriculum has been successfully piloted with the Pittsburgh community group, Health Black Family Project. A focus group of 19 individuals (18 African Americans and one Caucasian), ranging from their late 20s to mid 70s, helped to develop a five-module curriculum, says Meleah Himber, curriculum developer for Building Trust. Building Trust also worked with the local NBC television affiliate to create educational materials and public service programming for the community. Himber is based at the University of Pittsburgh School of Public Health (UPSPH). Both Thomas and Quinn worked at UPSPH in 2010 when the Building Trust project began, and it continues as a site for the program along with University of Maryland School of Public Health.

The UPSPH had previously created a community advisory board, and this group offered advice for the curriculum as well. The team also reviewed literature on minority participation in research and sought advice from other projects such as EDICT. Himber explains that the program also includes handouts, video clips, role playing, and case studies. The community curriculum has five modules, each two hours. They can be scheduled on a weekly, biweekly, or even monthly basis.

Each module also includes expected outcomes:
Figure 3: How often, if ever, do you think participants in medical research are pressured into participating?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percentage</th>
<th>African Americans (n = 1168)</th>
<th>Latinos (n = 1255)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>20%</td>
<td>22%</td>
<td>20%</td>
</tr>
<tr>
<td>Occasionally</td>
<td>35%</td>
<td>37%</td>
<td>35%</td>
</tr>
<tr>
<td>About half of the time</td>
<td>25%</td>
<td>23%</td>
<td>25%</td>
</tr>
<tr>
<td>Most of the time</td>
<td>15%</td>
<td>12%</td>
<td>15%</td>
</tr>
<tr>
<td>Always</td>
<td>3%</td>
<td>5%</td>
<td>3%</td>
</tr>
</tbody>
</table>

1. **Using Research to Improve Our Health.** Outcome: Appreciate the contributions of research for improving human health and eliminating health disparities. The program starts with an introduction of research and talk about the differences in disease and death rates among minorities. Participants discuss what makes research ethical, including informed and active participants who ask questions, and the difference between industry- and government-sponsored research.

2. **Learning from the Past: Protecting People Today.** Outcome: Recognize the impact of past abuses on the system of human subject protection in place today. Facilitators use a film clip on Tuskegee as well as a PBS documentary, and participants break into groups and discuss Tuskegee and other case studies of ethical abuse including Holmsburg Prison and Guatemala. “Our job is to train participants so they know that this cannot happen again when they are in control and know the regulations. We make sure everyone knows that they can become involved and even become members of a community advisory board or a local IRB,” says Himber.

3. **Making an Informed Decision.** Outcome: Make an informed decision about participating in research. This is a more didactic model. Discussion centers around different types of research (clinical, epidemiology, health services), risks and benefits of participation, therapeutic misconception payment for participation, rights of participants, IRBs, key questions to ask the researcher. Participants also get a brochure from OHRP that is available in English and Spanish.

4. **Becoming an Informed Consumer.** Outcome: Become an informed consumer of health and medical research results reported in the media. Participants receive a reading guide that helps them answer questions about research stories they see on the news. They also learn how to look for original sources and how to find out more at their local library.

5. **Getting Involved with Research.** Outcome: Explain approaches for getting involved with researchers and in research.

The community education modules are available currently to research professionals on DVD or hard copy, says Himber.

### Researcher Curriculum

Thomas says the curriculum for researchers has societal, organizational, and individual goals. They are:

- Achieve health equity
- Eliminate health disparities
- Increase community-engaged health research
- Enhance cultural confidence
- Recognize complexities of minority mistrust
- Develop inclusive process of informed consent
- Engage minorities in the research process

The curriculum for researchers is in the final draft stages and will be presented to research professionals at the annual meeting of Public Responsibility in Medicine and Research (PRIM&R), December 1-4, outside Washington, DC, at National Harbor, MD (www.primr.org). Resources for the curriculum include literature and an online survey and one-on-one interviews with investigators. Himber says the information honed from these interactions is still being deconstructed.

The curriculum initially had five modules, but a sixth has been added to distinguish between recruitment and retention of minorities. Each module includes an expected outcome and objectives. They are:

1. Examine non-scientific dimensions of research that impact the researcher’s engagement with the minority community.
Objectives:

a. Identify the impact of race, racism, ethnicity, socioeconomic status, and power on researcher's interactions with minority communities.

b. Recognize how historic injustices in both health care and research toward minority populations can effect interactions with minority communities today.

c. Recognize how your attitudes, behavior, and interactions impact your relationship with minority communities.

d. Explain how researchers' attitudes, behaviors, and interactions foster openness to present and future research among community members.

2. Recognize how an atmosphere of trust and understanding leads to effective discussions of research with minority communities.

Objectives:

a. Describe the importance of social, cultural, and historical factors that might predispose minority communities to trust or distrust researchers.

b. Recognize the legacy of the collective memory of selected research abuses involving racial and ethnic or other vulnerable research subjects.

c. Demonstrate the communication skills necessary to discuss historical abuses and mistrust.

3. Examine selected best practices for building trust through the respectful engagement of minority communities in research.

Objectives:

a. Describe four roles minority communities can play as partners in the research process.

b. Develop minority strategies for ongoing engagement with minority communities.

c. Recognize the importance of local media partnerships in communicating to minority populations.

d. Analyze the impacts of employing minority members in research teams.

4. Enhance the effectiveness of respectful recruitment in racial and ethnic minority communities.

Objectives:

a. Recall non-scientific dimensions of research that impact the researcher's engagement with minority communities.

b. Recognize the perception of the historical relationship between your institution and the community.

c. Anticipate potential challenges that may arise when reaching out to minority communities.

d. Compare and contrast factors that facilitate or hinder communication during the recruitment process.

e. Identify the effects of physical location and setting on the research recruitment process among minority populations.

5. Enhance the effectiveness of the informed consent process with racial and ethnic minority participants.

Objectives:

a. Distinguish the process of consent from the documentation of consent.

b. Compare and contrast factors that facilitate or hinder communication during the informed consent process.

c. Recognize culturally tailored informed consent materials and processes.

d. Identify the effects of physical location and setting on informed consent process among minority populations.

e. Apply knowledge and skills to create and effective informed consent process.

6. Design an effective plan for the retention of a minority population that fosters individual sense of belonging and community engagement.

Objectives:

a. Recall that effective recruitment is important for effective retention.

b. Review the significance of social, cultural and historical factors as they apply to a retention plan.

c. Examine case studies that are designed to foster individual sense of belonging and community engagement.
d. Apply what you’ve learned in this program to create a successful retention plan that could be used in your own work.

The researcher’s curriculum package includes the modules as well as trigger films, background segments from webinars and other presentations, and a facilitator’s guide. Quinn and Thomas say they are looking for investigators, IRBs, and other research professionals who would be willing to participate in a pilot of the curriculum. (Interested researchers can send an email to: info.healthequity@umd.edu).

Conclusion

There is a distinct under-representation of minority populations in all forms of research. There also are numerous studies that have identified significant health disparities in minority populations. Many researchers assume that this disconnect is based solely on the mistrust created by the Tuskegee Study. But this is not the case. Trust in the research process and willingness to participate as subjects can be improved with institutional commitment. Other issues must be addressed including additional funding, institutional commitment and mentorship of minority researchers, and increasing access to research for minority communities.

The Building Trust program has demonstrated, both in the survey results and the community curriculum pilot, that the goal is achievable. The research curriculum will provide more insight for investigators, coordinators, and IRB professionals who interact with minorities. “It is crucial for researcher and research institutions to find leaders in the community to work with as partners,” says Savage. “In order for barriers to be removed, people need to feel comfortable and building that kind of relationship is done over time. Be honest and transparent.”

References
7. Dr. Donald W. Prinz. The Atlanta Journal, July 27, 1072, p. 2