

Virtual Mentor
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Ethical Challenges in Community-Based Participatory Research

From the Editor

- Making House Calls on the Community** 77
Kenshata Watkins

Educating for Professionalism

Clinical Cases

- Communicating Results of Community-Based Participatory Research** 81
Commentary by Consuelo H. Wilkins
- Physician, Neighbor, Researcher—Conflicting Roles in Community-Based Participatory Research** 86
Commentary by Carla C. Keirns and Florence Thicklin
- Setting the Agenda for Community-Based Participatory Research—What Ethical Principles Apply?** 94
Commentary by Jessie Kimbrough-Sugick, Jessica Holzer, and Eric B. Bass

The Code Says

- The AMA Code of Medical Ethics' Opinion on Population-Based Genomic Research** 100

Journal Discussion

- Improving Institutional Review of Community-Based Participatory Research Applications** 102
Andrew Plunk
- Identifying the Challenges in Community-Based Participatory Research Collaboration** 105
Timothy Hotze

Clinical Pearl

- Routine HIV Testing in Older Adults** 109
Lisa K. Fitzpatrick

Law, Policy, and Society

Health Law

- Genetic Research among the Havasupai—A Cautionary Tale** 113
Robyn L. Sterling

Policy Forum

- Community-Based Participatory Research and the Academic System of Rewards** 118
Nicolette I. Teufel-Shone

Medicine and Society

- “Vulnerable” Populations—Medicine, Race, and Presumption of Identity** 124
Karla F.C. Holloway

Resources

- Suggested Readings and Resources** 128

- About the Contributors** 136

Upcoming Issues of *Virtual Mentor*

- March: Health Information Technology and Clinical Practice
April: The “R” Word—Ethical Allocation of Medicine’s Services
May: The Country Doctor
June: Allopathic Medicine’s Interface with Comparative and Alternative Treatments

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FROM THE EDITOR

Making House Calls on the Community

Justice. As physicians, we hardly ever think of ourselves as arbiters of such a thing—individual bodies, after all, are not seats of justice or injustice. Yet its pursuit is one reason why many of us chose to learn the art of medicine. The social and medical ills that bleed into one another are too often encountered by communities that are denied access to healthy living. This intersection of social and medical ills is precisely the focus of community-based participatory research (CBPR). While not a panacea, this crucial intervention is geared not only toward uncovering and understanding disparities, but also toward empowering the very people made invisible by them; with CBPR, everyone has a seat at the table. Dr. Meredith Minkler, one of the pioneers of CBPR, historicizes our understanding of the field by describing its roots as

most deeply grounded in the more revolutionary approaches to research that emerged, often independently from one another, from work with oppressed communities in South America, Asia, and Africa in the 1970s.... [D]eveloping countries' scholars developed their alternative approaches to inquiry as a direct counter to the often "colonizing" nature of research to which oppressed communities were subjected, with feminist and postcolonialist scholars adding further conceptual richness [1].

In the United States, communities of color and low-income populations are especially vulnerable to hypertension, kidney disease, diabetes, environmental morbidities, cancer, and, of course, heart disease—every health professional can rattle off the list of “who’s who” in the game of At Risk. Though efforts to treat these comorbidities must continue, the socioeconomic contributors to their pathogenesis demand our urgent attention as well. Social context and its effects on health are not solely the responsibility of sociologists, public health scientists, and anthropologists. It is also the responsibility medical students, residents, and physicians to see not only the patients sitting in front of us, but the stories they bring with them into our office.

In some ways, CBPR is the spiritual heir of the practice of making house calls. These visits afforded the physician a closer look at the patient’s environment, family dynamics, and diet; the diagnostic lens was wider than in the now-typical “snapshot” interaction. CBPR affords physicians the opportunity to restore that practice and see the motion-picture context that gives meaning to the still frame frozen in a patient’s chart.

Perhaps the time has come for us to make “house calls” on the community. Around the country, CBPR partnerships are in action. At the Detroit Urban Research Center, physicians and their partners are working to relieve the burden asthma has placed on inner-city Michigan communities and spearheading various interventions to improve the incidence of diabetes and kidney disease. Morehouse School of Medicine is well known for its CBPR programs, especially the Community Based Research Cancer Unit. One of the unit’s foci is eliminating racial disparities in breast and cervical cancer. There has also been a promising increase in funding for CBPR. In 2002, the prestigious Robert Wood Johnson Foundation expanded its Clinical Scholars Program to include CBPR because the organization saw that

no longer can physician-scientists design research studies in a vacuum and expect that subjects will participate and embrace such findings as research. It is clear that in the 21st century, the public must have input into the conceptualization, design and execution of research studies with the medical scientists [2].]

There *is* no panacea for health disparities, but as researchers we know that every step in the methodological process vibrates with the sobering potential to change lives. Therein lies the impetus for this issue of *Virtual Mentor*.

Great care must be taken when any human subject is involved in research, but especially when those subjects are part of communities made vulnerable by historical and contemporary marginalization. The ethical concerns specific to cases outside the boundaries of conventional clinical research are discussed in this month’s clinical case commentaries. In the first case, Carla C. Keirns, MD, PhD, MSc, clinical ethics director of the history of medicine program at Stony Brook University, and a former Robert Wood Johnson Clinical Scholar, and Florence Thicklin, a community-engaged research consultant and community partner with the University of Chicago’s South Side Health and Vitality Studies, offer their guidance about the balancing act demanded of a neighbor and a physician-researcher.

Consuelo H. Wilkins, MD, MSCI, director of CARE in Our Community and associate professor at Washington University School Medicine, comments on the dilemma physician-scientists can find themselves in when community members become upset about the results of CBPR. How should practitioners negotiate the disclosure of results, particularly when they threaten to paint a community in a less-than-positive light? In this particular case, CBPR uncovers a high rate of sexually transmitted diseases in the community, including HIV/AIDS. Lisa K. Fitzpatrick, MD, MPH, professor of medicine at Howard University, tackles the topic of missed HIV diagnosis among older adults in this month’s clinical pearl.

With the media covering the suicides of several gay teens linked to bullying and societal pressure, our third case is unfortunately quite timely. Oftentimes, community partnerships involve religious organizations, due to their steadfastness and membership base in communities. Johns Hopkins’ Jessie Kimbrough-Sugick, MD, MPH, Jessica Holzer, MA, and Eric B. Bass, MD, MPH, editor in chief of *Progress*

in Community Health Partnerships, provide guidance for health professionals about the nuances of framing the research topic in terms acceptable to socially conservative community partners.

As CBPR gains traction, questions arise about how it fits into the traditional research system. As Tim Hotze, a senior research assistant at the American Medical Association's Institute for Ethics, writes, the differences between the ethical underpinnings of traditional research and those of CBPR are becoming better understood, but the means for accommodating CBPR's special ethical demands remain to be worked out. In his journal discussion, Andrew Plunk, MPH, reviews an article that explores the ways in which institutional review board (IRB) approval forms privilege traditional research methods, which can hinder the ideals of CBPR and even harm community participants, and how changes in form language can ensure the quality of community-based research proposals. Similarly, Nicolette I. Teufel-Shone, PhD, a professor with joint appointments in both anthropology and public health at the University of Arizona, examines the ways CBPR achievements are incompatible with those considered important to academic career-building and tenure review.

This month's health law piece by Robyn L. Sterling, JD, MPH, underscores the importance of adhering to community-based research ethics, especially in the face of research pressures to do otherwise. She looks at the experience of the Havasupai Tribe, whose genetic material was used for research other than that for which they had consented, causing damage to the tribe and its relationship with Arizona State University's researchers. A complementary excerpt from the American Medical Association's *Code of Medical Ethics*, "Safeguards in the Use of DNA Databanks in Genomic Research," contains provisions designed to prevent just this kind of misuse of data and mistreatment of research participants.

The crux of CBPR hinges on the parameters of our definitions of "community," and how we create the borders of our own and our research subjects' identities. This is an enormously volatile concept because it threatens to shift the community autonomy that CBPR aims to empower back into the hands of outsiders, in the guise of well-meaning CBPR practitioners. In the medicine and society section, Karla F.C. Holloway, PhD, MLS, of Duke University, forces us to look beneath our white coats at the prejudices we may not even be aware of even as we perpetuate them.

There is no hiding from the progress that still needs to be made. We must take part in cultivating the transparency and levers for advocacy that CBPR offers. We must ask our policymakers to partner with us to create legislation congruent with a community-based approach to research. We must refuse to stay within the cozy confines of our comfort zones or treat patients' bodies as separate from their lives. And most importantly, we must follow the lead of community members when we work in partnership, instead of assuming that we can diagnose and treat families, neighborhoods, and ethnic groups from afar.

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CLINICAL CASE

Communicating Results of Community-Based Participatory Research

Commentary by Consuelo H. Wilkins, MD, MSCI

Drs. Allen, Seymour, and Lesh of Barclay University Hospital had been working in conjunction with the New Hope Church and Grass Blade Youth Community Center to study the link between incarceration and sexually transmitted infection (STI) rates in the Park neighborhood. The findings were striking in the physicians' minds, revealing that far greater numbers of the community members than expected had histories of incarceration and STIs. The physicians were concerned because they had worked hard to convince the community to allow them into the neighborhood and did not want to alienate residents. Yet they felt the community members had a right to know the facts.

On the day designated to share the findings, the church annex was packed with familiar and unfamiliar faces. Members of the Grass Blade Youth Community Center and eight volunteer members of New Hope Church were present. The church group, headed by Reverend Mason, served as the voice of the community.

The physicians began going through their data, stating that 3 out of 5 males had been incarcerated by the age of 25 and had had an average of 2 STIs by that age. Out of this 60 percent, 25 percent were HIV positive. Reverend Mason was outraged and stood up to leave before the presentation was finished, but not before saying, "We welcome you into our community, and this is the so-called research you do. You paint our community as a sinful, violent place to live. How will this research affect our young people who will think that growing up means going to prison and getting AIDS? What about employers' decisions when community members are applying for jobs? When our youth are applying for college?"

The physicians tried to explain that the research was done without bias and with the sole purpose of creating interventions.

Other community members started to exclaim, "My children have never been to prison and don't have any diseases!" Soon, the packed room emptied, save for a few members who were trying to convince people to "hear these doctors out; after all, we do need help." The research team was disappointed. They believed they had communicated the purpose of the research to the community before they began their work. Obviously more people attended this conclusion meeting than the earlier informational one.

Commentary

Discord over the dissemination and publication of research results is among the most common conflicts that occur between research partners in the community-based participatory research (CBPR) setting [1]. It is important to resolve these disagreements in a timely manner to maintain the integrity of the research process and sustain the partnerships.

The fundamental issue in this case is that the academic researchers are acting independently of the community when interpreting the data and planning to disseminate the research results. Although the researchers are firm regarding the importance of providing feedback to the community, they failed to discuss the results of the study with the community partners prior to the public forum. Both the academic and community partners should have been involved in the data interpretation, which would have allowed ample opportunity for discussions about the validity of the data and the potential implications of the study results. After the data were interpreted and discussed jointly, the academic and community partners should have been jointly active in the dissemination efforts. In this case, the community leaders were a part of the audience. By acting independently, the researchers violated an essential element of CBPR—shared authority between the partners.

A key component of CBPR is the establishment of effective, meaningful, and mutually beneficial partnerships between academicians and community members [2]. Although these partnerships are vital for the conduct of CBPR, their complex nature creates many opportunities for the divergence of opinions and interests. Even in the most successful academic-community partnerships, there are likely to be disagreements, so it is imperative to have a plan for conflict resolution. If a prospective plan for conflict resolution had been prepared, all members of the partnership would have had the opportunity to discuss their concerns, and disagreements could have been resolved prior to the open community forum.

There is a common misperception that community partners have limited expertise to offer in some stages of the research process [3]. Community partners are valued for their ability to recruit volunteers or facilitate data collection, but often their input is not sought during the grant writing, study design, and data interpretation stages because these activities are thought to require skills only obtained through formal training. While community members should not be expected to manage large databases or perform statistical analysis, their knowledge of the community can help insure that factors that could influence the results are considered, and they can help frame and interpret the research results [4, 5].

In this case scenario, 60 percent of the young men in the study had been incarcerated and a substantial number had STIs including HIV. On the surface, there is no factual reason to doubt that the researchers are presenting the actual results of the study; however, the results differ significantly from those expected by both the researchers and the community. The researchers should have engaged the community partners in

discussions about factors that could contribute to the higher-than-expected rates of incarceration and STIs.

Perhaps the researchers would have learned from the community partners that the primary site of the study, the Grass Blade Youth Community Center, works closely with the juvenile courts and the state's early prison release program on a project for ex-offenders that has been highly successful in offering educational opportunities and facilitating job placement for the young men. Young men from around the region participate in the program, so many of the men in the researchers' study do not actually reside in the Park neighborhood where the community center is located. With this information, the researchers may consider additional analyses using variables, such as residential addresses and zip codes that would more accurately reflect the frequency of incarceration and STIs in the Park neighborhood.

The community partners might also suggest other strategies to insure that the results are representative of the community, such as changing the primary day of data collection from Monday to Thursday because more young men from the Park neighborhood visit the community center on Thursdays to participate in the basketball league.

If it is determined that the data collected are from a representative sample of the Park neighborhood and potential confounding factors have been eliminated or controlled for, both the community and academic partners should agree on how the data will be presented to the community. The partners must not alter the research results but should present them to the community in a clear, easily understandable, culturally sensitive, useful, and empowering manner [6]. For instance, if the results are expressed in scientific and medical terminology rarely used outside the academic setting, the community may be less likely to understand or believe the results. If, on the other hand, the results are presented jointly by the academic and community partners in easily understood language, the community is more likely to accept the results and work with the partners to develop and implement interventions.

The following two examples of messages about the same research results are likely to generate very different responses from the community.

Drs. Allen, Seymour, and Lesh: Sixty percent of the young men in the Park neighborhood have been incarcerated by the age of 25 years. The average young man in the Park neighborhood aged 15-25 years old has had two sexually transmitted infections, and 25 percent of them have HIV infection.

Dr. Allen and Reverend Mason: Among the young men in our study, we found higher-than-expected rates of incarceration and sexually transmitted infections, especially HIV. These findings are very concerning to all of us. We must work together to better understand the factors contributing to incarcerations and sexually transmitted infections and to ultimately reduce these rates.

To avoid the types of misunderstandings and conflicts seen in this scenario, it is imperative that partners in CBPR develop mutual and respectful trust to facilitate the shared authority necessary to conduct CBPR. Both the academic and community partners should have well-defined responsibilities that are clearly indicated in a memorandum of understanding (MOU) or similar document. The MOU should include provisions for conflict resolution to avoid the dissolution of partnerships.

Because data dissemination is one of the most common areas of conflict among community and academic partners, it is important to develop a plan for data dissemination and authorship prior to the start of a study [7]. In CBPR, the academic and community partners share ownership of the data, so researchers should neither present nor publish data without the consent of the community partners, and vice versa [8]. Although the ownership is shared, neither partner should maintain veto power. Instead, partners should agree to continue discussions until a resolution or compromise is reached, even if it involves inviting a third party to mediate [9].

In addition to a plan for conflict resolution, a prospective discussion of data interpretation and dissemination should occur. Potential questions include:

- Should there be any restrictions on the dissemination of data that are unanticipated or potentially harmful to the community?
- Is there a plan for framing and disseminating negative data or data that contribute to formation or maintenance of stereotypes and prejudice?
- Will community partners be included in decisions about scientific publications?

Because conducting CBPR is a complex and dynamic process involving partners with a variety of interests, disagreements are likely to occur. Managing conflicts is easier when the partners have developed a mutually respectful relationship and there is a written agreement at the start of the study. Stages in the research process that are more likely to result in discord should be anticipated and discussed early in the process to facilitate a quick resolution. With adequate planning and a detailed MOU, conflicts may not be avoided, but they are more likely to be resolved in a manner that will facilitate the research and improve the health of the community.

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Related in VM

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CLINICAL CASE

Physician, Researcher, Neighbor—Conflicting Roles in Community-Based Participatory Research

Commentary by Carla C. Keirns, MD, PhD, MSc, and Florence Thicklin

Dr. Banks moved to the mixed-income neighborhood where he also works at the Dunlap Community Health Center. Outside of the clinic, he serves as a member of the neighborhood association and is getting to know many of his neighbors, little by little, through the association and potlucks and chance meetings in the grocery store. At the clinic, he's asked to be part of a community-based participatory research project to study "Safe Sex Practices in Dunlap, Zone 4," a topic he's long been interested in exploring. He anticipates that recruitment will go fairly easily since he has begun to build relationships within the community. When recruitment begins, he notices that he is getting strange looks from his neighbors, and his relationships with them are starting to appear strained.

After a couple of weeks of low recruitment numbers, Dr. Banks decides to offer an incentive. Quite a few people from the neighborhood consent to participate after word spreads of the grocery store gift card given upon completion of the 1-hour interview. His first several groups of participants are neighbors on his block, some of whom are married. Each interview is more difficult than the one before it, and he finds that he is left with little data after each.

After a few more unsuccessful interviews, Dr. Banks brings the matter up with his colleagues and community members. One whom he really trusts says, "Dr. Banks, you have to choose. Be a neighbor or be a physician-researcher. No one will open up to you as long as you are both. People feel that you might share whatever you learn about individuals with other neighbors."

"But it was clear on the consent form that no data on individuals would be released," Dr. Banks says.

"That's all fine," says his colleague, "But people don't trust you with their personal information. They don't want you to know."

Dr. Banks feels pulled in two directions. He doesn't think that data he's collected so far will be at all helpful. He really cares about the work he's doing and wonders if there is a way to exist in both worlds.

Commentary 1

by Carla C. Keirns, MD, PhD, MSc

Dr. Banks wants to improve the health of his community, reduce health disparities, contribute to scientific knowledge, and advance his career. As a physician-researcher, he hopes to do all of these through his personal clinical services at the Dunlap Community Health Center and community-based participatory research on the health challenges of his community. By moving into the neighborhood, going to potlucks, and getting to know the community, he has done all the right things to start a practice in community-based primary care and projects in community-based participatory research [1].

Physician, Researcher, or Neighbor?

The problem Dr. Banks faces now is one of role confusion [2]. As he was told, “Be a neighbor or be a physician-researcher. No one will open up to you as long as you are both.” The social rules of neighborly interaction vary from one community to the next, but generally include knowing each others’ spouses and children and may include school, church, or other community activities. At the same time, there’s an implicit understanding of respect for privacy: the role of neighbor is not easily compatible with knowledge of the sexual activities of everyone on the block.

In addition to the conflict between neighbor and researcher, Dr. Banks also faces a conflict between his roles as neighbor and physician, and another between his roles as physician and researcher [3]. Physicians working in close-knit communities, whether small towns or urban neighborhoods, have to manage relationships with people who may be simultaneously patients and neighbors, friends, and business associates. Managing these multiple roles to protect confidentiality and trust and avoid exploitation or misunderstanding requires balancing responsibilities and careful communication [4]. The intertwining of personal and professional relationships may sometimes require the physician to hold himself or herself apart from highly charged social interactions [5], particularly dating and sexual relationships, which are often most prone to miscommunication for both patients and physicians [6]. This may be particularly challenging for the physician who is unattached and has to decide whether to date within or only outside of the community.

“Are you my doctor or are you a researcher?” Are you advocating for the individual patients in the study, for scientific truth, for the pharmaceutical company or agency paying for the research, or for something else? These conflicts between loyalty to research participants and other stakeholders are often more apparent to community partners than they are to the researchers themselves. I have sat in research planning meetings in both the U.S. and Africa in which community members initiated explicit discussions of the incentives for researchers, asking about who was paying for research, what questions are being asked, who chose those questions and why, and what was the value to the individual researchers of doing and publishing the research in terms of their careers. These women—and they were all women, usually teachers

or nurses professionally—representing themselves and their communities, brought with them a more sophisticated awareness of the history of relationships between poor communities and researchers [7, 8] than the researchers themselves often did.

In Philadelphia, for instance, there is widespread community awareness of dermatologic and pharmaceutical research conducted at Holmesburg Prison that left many men with severe burn-like scars, and generated new products like Retin-A for acne [9]. Researchers, most of whom were raised or trained elsewhere because of the social dynamics of academic careers, do not learn of this community history from their fellow researchers and mentors, nor from their local neighbors. Community representatives frequently argue that researchers have been studying their communities for decades without either finding practical solutions to the health problems at hand—such as studies of diabetes in Native American communities [10-12]—or helping the communities gain access to health care, including the benefits of both the research in question and prior community-based research [13]. What is remarkable is not that the community representatives so often advance the critique that, due to structural injustice in access to health care, research benefits the researchers but neither the participants nor their communities, but that this criticism is always a surprise to the researchers. Seeing research as an intrinsic and communal good, researchers often fail to consider how the benefits of research reach—or do not reach—community members [14].

Community-Based Participatory Research for Health: What Can Dr. Banks Do?

Dr. Banks has worked hard to be accepted as an insider in Dunlap, a neighbor and a physician, and now wants to participate in community-based participatory research (CBPR) to improve the health of the community. The case description does not include a discussion of the origins of the study “Safe Sex Practices in Dunlap, Zone 4;” who planned it, and why.

Most important, who represents the community? What is the structure of Dunlap, demographically, economically, socially? These questions are essential to beginning any CBPR project because, especially in communities—usually economically disadvantaged and often ethnically diverse or composed primarily of members of historically discriminated-against ethnic groups—that face substantial health disadvantages, community leaders need to be identified and legitimate in the eyes of community members [15]. Balance may be necessary between groups to ensure representation and attention to issues which may affect one segment of a community more than others—as in U.S. cities where I have worked with both African American and Latino communities—and longitudinal relationships of trust and equality are essential to continuing collaboration between researchers and communities.

Next, who decided that sex was a good first topic for a new CBPR collaboration? Safer sex may be an important issue epidemiologically in Dunlap, as it would be in nearly any community, but CBPR principles require community participation in the selection of research topics, the choices of methodology, and the interpretation of

results. While safer sex may be a topic this CBPR collaboration could handle as a second or third project, once trust has grown and research protocols are more developed, it's probably too sensitive a topic for the first project unless the community itself identifies it as its most pressing health problem (as some communities indeed would have).

If the CBPR collaboration decides in the future to take up safer sex, Dr. Banks' status as an insider, as well as the value of his time as a clinician, suggest that they should probably consider the use of "outsider" professionals to serve as the interviewers, selected by both the local health experts such as Dr. Banks and the community partners, to increase protection of confidentiality. Failure to consider interviewer effects in sexuality research has been a confounding factor since the famous Kinsey studies of the 1940s, in which both male and female respondents were initially interviewed face-to-face by the same middle-aged male researcher, perhaps contributing to apparent underreporting of female respondents' admitted sexual activity and exaggeration of the responses of male subjects [16, 17].

Dr. Banks has several choices, all familiar to researchers in CBPR, sexuality research, and social science research more broadly. The work of building trust with a community is ongoing, and whether as a researcher or neighbor, asking about sex at the potluck is probably unwise. He can facilitate community health, participate in CBPR, and maintain his status as an insider in his community, but only if he acknowledges the conflicts inherent in these roles, and decides deliberately which specific activities would benefit from his direct participation, and which roles are best filled by others.

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Commentary 2
by Florence Thicklin

Dr. Banks displayed a lack of respect for his community by being insufficiently up front about his research; the community's lack of trust was demonstrated by their reluctance to share personal information.

Researchers can incorporate community engaged practices into traditional research projects through the community-based participatory research (CBPR) model. CBPR is:

a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities [1].

CBPR is a balancing act between two partners with emphasis on community engagement throughout the research process. While researchers must be mindful of fostering community relationships, they must avoid the development of unethical partnerships.

To earn trust, Dr. Banks must be transparent about his intentions to conduct research in his community. He attempted to achieve a level of acceptance by acculturating to his new community, but it isn't enough for him to just *be located* within it; the community must be a part of the development of, implementation of, and dissemination of findings from the research.

Had Dr. Banks used community social functions to create awareness of his intentions to conduct CBPR and invited community members to participate in research development, perhaps community concerns or mistrust of researchers would have surfaced. It appears that Dr. Banks got to know the community, but the community did not get to know Dr. Banks as a researcher. The level of community engagement for his study does not satisfy CBPR principles.

For Dr. Banks' research to be successful, it should benefit the community and not just further his personal research interests. As histories of indigenous communities demonstrate, "outside research teams swooped down from the skies, swarmed all over town, asked nosy questions that were none of their business and then disappeared never to be heard of again" [2]. Dr. Banks doesn't have to do that. He can overcome his neighbors' understandable distrust.

He can support programs that will provide practical applications of his research to benefit the community. He can involve community members in the development of research instruments; assure the protection, privacy, and confidentiality of research participants; hire and train community members as interviewers; and secure additional funds or resources to support other community initiatives [3]. He can acknowledge and describe the researcher's role in the study, obtain the community's permission to give credit for contributions to manuscripts for publications and study reports to sponsors, and include community members in presentations at professional meetings. If Dr. Banks follows the CBPR approach, he can continue to conduct his research, while serving and collaborating with the community.

Although Dr. Banks' study received institutional review board (IRB) approval, collaboration with the community was not standard. Its role was limited to that of subject, when it should rightly be a partner. The overall goal of the IRB CBPR ethics review is to ensure the community's appropriate participation in research, minimize

adverse impacts of research, and maximize the potential benefits to individuals and the community as a whole. An additional review to make sure these criteria are met can be carried out by a community advisory board [4]. Human protection concerns in CBPR are not just about the individual, but also inherently about respect for, beneficence toward, and just treatment of the community [5].

Dr. Banks must demonstrate that he is not just conducting another study with no commitment, but undertaking a community-engaged process with mutual benefits. The advantage to the CBPR approach includes Dr. Banks' ability to contribute scientific research, the community partners' knowledge of familial aggregation and cultural and historical community dynamics, and an empowering co-learning process that attends to social inequalities.

Using a memorandum of understanding (MOU) would increase the community's trust. This document establishes decision-making styles; intent to compromise among different philosophies; mutual respect; shared responsibilities; respect for diversity of gender, race, ethnicity, class, age, and so on; preferred language and definitions of terms; and ownership of data. Furthermore, partnerships can dissolve and need to plan a process for closure [6].

The participant screening process must also reflect these priorities. During this process, the researcher determines if potential participants meets eligibility requirements and if they will be compliant with study requirements. In addition to signing a consent form, participants should be given a verbal explanation of all of the elements of informed consent: the purpose of research (in this case, the sensitive nature of the topic), risks, benefits, alternatives, who will have access to the data, a certificate of confidentiality, and so on. The researcher must make sure the participant actually comprehends the study expectations. Participants' desire for privacy must be respected.

CBPR partners must work together to make sure the research is conducted with the best interests of the community in mind. The research must also be designed with a specific understanding of the community in which it is taking place. Researchers and community partners must establish agreed-upon values and goals and focus on measurable outcomes and accountability to each other. They must treat each other with respect, trust, sincerity, and commitment; make communication and mutual understanding a priority; balance power and share resources; and work to address the needs of all partners.

Is Dr. Banks' Community Too Small for Such Personal Research?

Small towns and communities must be considered for research; they should not be neglected on the basis of population size. But only a very carefully designed study will maintain the confidentiality and de-identification of study participants and not stigmatize or bring harm to the community. CBPR can be successful in small communities if partners practice the principles of good community-campus partnerships.

Terminating the study would be extreme and a disservice to his community. However, if Dr. Banks redesigns the study and integrates the principles and ethics of CBPR, he can fulfill his research objectives and meet the community's needs without being estranged from it.

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CLINICAL CASE

Setting the Agenda for Community-Based Participatory Research

Commentary by Jessie Kimbrough-Sugick, MD, MPH, Jessica Holzer, MA, and Eric B. Bass, MD, MPH

Dr. Peck, an academic researcher, is looking into the correlation between teen suicides and peer bullying around the country. He goes to Frederick Heights because that community has had two suicides in 3 years, a high occurrence for a small community. His colleague, a psychiatrist, sees several youths from the community, and these patients have reported disturbing patterns of bullying. A Frederick Heights community group has established positive partnerships with other researchers from the local university, and Dr. Peck feels it is best to meet with this group before proceeding with the study. Dr. Peck speaks with the community group's board of directors to gauge their interest in a study that explores interventions to prevent bullying.

Most of the board members are part of the congregation of a conservative church. In the meeting, members state that the two boys who committed suicide were homosexual and that being gay is wrong. They say the research is neither important nor relevant in their community in spite of the statistical data. The board chairperson attempts to open the members' minds to the research idea by saying, "I know this is a difficult subject to talk about, but it doesn't mean those with 'alternative lifestyles' who live in our community don't deserve our protection."

His words are drowned out by phrases like, "Not here they don't." One member says, "I think the board should be focused on bringing research to the community that looks at the positive effects of religion on teen vandalism. Because you know we started a Friday night Bible class for young adults about a year ago, and there has been less graffiti and loitering."

Commentary

This case highlights important ethical issues that may arise when researchers and community leaders who seek to engage in community-based participatory research (CBPR) discover they have conflicting values.

Conflicting researcher and community agendas can lead to ethical dilemmas that might be better understood using the principles of biomedical ethics. Those principles are respect for autonomy, beneficence, nonmaleficence, and justice [1]. Although primarily applied to individual interactions, such as those between a researcher and study participant, these principles should be applied to communities

as well. They may offer guidance to researchers approaching communities with the intent to engage in research on a sensitive topic.

Autonomy of the Community

In research, respect for the autonomy of individuals underpins the practice of informed consent, limiting the degree to which researchers and institutions can impose their own agendas on individuals, regardless of the potential benefit for those individuals [2]. An underlying assumption in CBPR is that the community has interests and agendas that deserve respect and deference from researchers [3]. This can be viewed as respect for the autonomy of the community, which lays the foundation for a genuine partnership between the researcher and the community.

In the case described above, Dr. Peck has come to the community with a research agenda in hand. His agenda is not that of the community, which leads to the conflict highlighted in the case. Respecting the community's autonomy—its right to pursue its own interests and values—demands developing a relationship with the community at an early stage [3, 4]. In this way, the community can exercise its autonomy in setting priorities for the partnership and the research in conjunction with the researcher. In this first phase, Dr. Peck should ask the community members about their needs and interests and how his proposed work might help meet those needs.

Conversely, Dr. Peck should ask himself, “Is my proposed research agenda driven by external factors (e.g., funding opportunities, personal interests, institutional priorities) that are controversial or not aligned with the community's agenda?” Dr. Peck assumes that his interest in understanding the causes of teen suicide so that no more teens will take their lives is shared by the group's board. He seems unaware of the complexity of his research interest and the controversy that surrounds it in the community.

Beneficence and Nonmaleficence in CBPR

While it is not expected that individual participants necessarily gain benefit from participation in traditional research [2], it is expected of CBPR that actions will be taken to improve or promote the health and well-being of community members [4]. In other words, CBPR should be beneficent—it should help the community [4]. Complementary to beneficence is nonmaleficence—do no harm—another fundamental principle in biomedical ethics [5]. Dr. Peck should ask himself, “Will my research bring benefit to the community, and is there risk of causing harm to the community or to the partnership?” If this conflict is not handled in a thoughtful manner, a study that shines more light on gay teenagers could harm rather than help those at risk. Unintended consequences may include mistrust and deterioration of the previously established partnerships between the community and other research entities. Moreover, without the support of the community, the research findings may be limited.

Social Justice in CBPR

The concept of social justice takes the form of communitarianism and egalitarianism in CBPR. The communitarian perspective argues for developing the obligations of the community to the individual and those of the individual to the community from principles that are pluralistic and derived from within the community, rather than from external sources [6]. Egalitarianism, on the other hand, is the view that individuals deserve equal treatment, especially in the case of essential goods, such as health care. The principles of egalitarianism are derived not from the community but from the more fundamental social acknowledgement that each of us wishes to be treated fairly. One principle of egalitarianism is that each individual has the maximum amount of liberty compatible with a similar allowance for others. A second principle is that inequalities in primary goods, such as health care, are tolerated only insofar as the system in which they exist benefits the whole and everyone has an equal opportunity to seek better status [6].

In this community, Dr. Peck has identified a troubling unfairness—gay teens are bullied to a greater degree than other teens. Suicides of gay teens have occurred recently, raising the prospect that increased bullying may be related to the increased occurrence of teen suicide. This is a public health and social justice issue that deserves attention. A researcher who sees such a troubling trend in a community reasonably feels a duty as a public health professional to address the problem.

The community's lack of interest in studying the relationship between teen suicides and bullying causes conflict between the board's communitarian view and Dr. Peck's egalitarian view. The board has expressed the values it believes are fundamental in this case, derived from the values of the community. Dr. Peck has expressed a more egalitarian view that especially bad treatment of a specific group—gay teens—merits investigation and amelioration.

The tension between the communitarian and egalitarian perspectives puts Dr. Peck in a difficult position. Does he work with the community on the issue of church outreach programs' effects on vandalism, delaying or potentially forgoing development of interventions that may save the lives of vulnerable teens? Does he separate himself from the community group and go his own way to address the teen suicides and bullying?

The risk of not investigating teen suicide is that a significant public health concern may go unaddressed and that vulnerable persons within the community may continue to suffer. Dr. Peck could establish a relationship with the community's board in the hope of convincing them of the ethical imperative to pursue social justice in their community. In the interim, however, his agenda would not be advanced and there would be no guarantees it ever would be addressed.

Practical Options for Addressing Ethical Concerns and Conflict in CBPR

To minimize conflict between community autonomy and the researcher's aim for community health and wellness promotion, Dr. Peck should have done more

preparation for his meeting with the community's board. At the very least, he needed to know what community stakeholders were represented on the board, in this case, primarily members of a conservative church who judged gays negatively. This knowledge might have enabled Dr. Peck to frame his research in terms of the generalizable consequences of bullying, suicide, and copycat suicides among adolescents—regardless of the impetus.

Seeking common ground and interests within the community could have led to a more satisfying experience and research partnership [2]. Dr. Peck should have identified and reached out to potential allies such as the board's chairperson and others in the community. Furthermore, he should have engaged the board's chairperson as a lead collaborator in the development of the research [7]. Bringing other community voices to the table [4], such as those personally affected by the suicide tragedies, might have lent substance and humanity to the discussion between Dr. Peck and the board. Finally, Dr. Peck might have reached out to public health officials, school boards, parent organizations, and town councilpersons to achieve community-wide understanding of the issue, build consensus, and identify strategies to address the public health problem.

All is not lost. Dr. Peck can still study teen suicide in Frederick Heights, despite the board's objections. He must, first and foremost, ensure good lines of communication between himself and the community's board [8, 9]. Good communication can form the basis for resolving or minimizing conflict, just as impaired communication can cause or aggravate conflict. He should seek counsel from respected colleagues and community leaders outside the board [10]. In the clinical setting, a hospital ethics committee is available for conflicts involving patient autonomy and provider intentions regarding beneficence and nonmaleficence [11]. In the CBPR setting, there may not be an equivalent ethics committee other than an institutional review board. However, seeking advice from colleagues in and out of this field of research, as well as nonresearchers related and unrelated to the town, might prove helpful in sorting out the complexities of the conflict and salvaging the research relationship.

Alternatively, Dr. Peck and the board may reach a point where they agree to disagree [10]. In that instance, Dr. Peck may pursue his research interests without the help of the board. If he establishes relationships with other entities or members of the community, Dr. Peck may form a different partnership.

Regardless of whether or not Dr. Peck can reach an agreement with the community's board, it will be important for him to apply the principles of virtue ethics to his CBPR experience [12]. In situations of conflict, the virtues of compassion, courage, honesty, and humility all have a role. Dr. Peck's compassion for the victims of bullying should be accompanied by courage in expressing his concerns. In doing so, he will need to be honest about his interests and abilities, while also being humble enough to recognize that he cannot solve the problem without help from people in the community.

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THE CODE SAYS

The AMA *Code of Medical Ethics*' Opinion on Population-Based Genomic Research

Opinion 2.079 - Safeguards in the Use of DNA Databanks in Genomic Research

The following safeguards should be applied to the use of databases for the purpose of population-based genomic research:

- (1) Physicians who participate as investigators in genomic research should have adequate training in genomic research and related ethical issues so as to be able to discuss these issues with patients and/or potential research subjects.
- (2) If research is to be conducted within a defined subset of the general population, that is, an identifiable community, then investigators should consult with the community to design a study that will minimize harm not only for individual subjects, but also for the community. When substantial opposition to the research is expressed within the community, investigators should not conduct the study. When the community supports a proposal, investigators nevertheless should obtain individual consent in the usual manner. The same procedure should be followed whether the investigators intend to collect new samples and data or whether they wish to use previously archived data sets.
- (3) When obtaining the informed consent of individuals to participate in genomic research, standard informed consent requirements apply (see Opinion 2.07, "Clinical Investigation"). In addition:
 - (a) Special emphasis should be placed on disclosing the specific standards of privacy contained in the study: whether the material will be coded (i.e.: encrypted so that only the investigator can trace materials back to specific individuals) or be completely de-identified (i.e., stripped of identifiers).
 - (b) If data are to be coded, subjects should be told whether they can expect to be contacted in the future to share in findings or to consider participating in additional research, which may relate to the current protocol or extend to other research purposes.
 - (c) Individuals should always be free to refuse the use of their biological materials in research, without penalty.

(d) Disclosure should include information about whether investigators or subjects stand to gain financially from research findings (see Opinion 2.08, “Commercial Use of Human Tissue”). Such disclosure should refer to the possible conflicts of interest of the investigators (see Opinion 8.0315, “Managing Conflicts of Interest in the Conduct of Clinical Trials”).

(e) Subjects should be informed of when, if ever, and how archived information and samples will be discarded.

(4) To strengthen the protection of confidentiality, genomic research should not be conducted using information and samples that identify the individuals from whom they were obtained (i.e., by name or social security number). Furthermore, to protect subsets of the population from such harms as stigmatization and discrimination, demographic information not required for the study’s purposes should be coded.

Issued June 2002 based on the report “[The Use of DNA Databanks in Genomic Research: The Imperative of Informed Consent](#),” adopted December 2001.

Related in VM

[Genetic Research Among the Havasupai: A Cautionary Tale](#), February 2011

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JOURNAL DISCUSSION

Improving Institutional Review of Community-Based Participatory Research Applications

Andrew Plunk, MPH

Flicker S, Travers R, Guta A, McDonald S, Meagher A. Ethical dilemmas in community-based participatory research: recommendations for institutional review boards. *J Urban Health*. 2007;84(4):478-493.

Those who promote community-based participatory research (CBPR) have long known that there are obstacles to its wider adoption. For example, Ahmed and colleagues cite several “institutional barriers” to CBPR, which include the objectification of the community in research, a lack of respect for community knowledge, and a limited understanding of CBPR, along with the perception that it lacks rigor, a lack of CBPR researchers to serve as mentors, and a dearth of available grants and incentives [1].

While Ahmed et al. made a significant contribution to our understanding of the difficulties facing a researcher interested in CBPR, Flicker et al. have recast the discussion and changed the way we should look at institutional influences on CBPR in their 2007 article “Ethical Dilemmas in Community-Based Participatory Research: Recommendations for Institutional Review Boards” [2]. The article reports on a study in which the authors performed a content analysis of forms and guidelines used by institutional review boards (IRBs) and research ethics boards (REBs) in the United States and Canada, respectively. Their sample comprised 30 institutions that offered graduate-level public health training, due to their belief that institutions with schools of public health would be the most sympathetic to CBPR.

Flicker et al. found that the forms used by the IRBs and REBs they studied tended to favor a traditional biomedical research framework, and they concluded that, by taking a narrow view of research from the outset, ethics boards could unknowingly harm communities by treating traditional forms of research as the *de facto* standard. They close their article by offering suggestions for more CBPR-friendly language for use in IRB and REB forms and policies [2].

Ahmed et al. were offering new ways to think about barriers to CBPR, thus their recommendations were necessarily vague—“redefine scholarship” and “hire CBPR champions,” for example [3]. Flicker et al. change the tone of the discussion by presenting specific instances of a real institutional bias favoring traditional research that not only have the potential to dissuade researchers from using CBPR, but also might hinder IRBs in determining what ethical CBPR actually is. While Ahmed et al.

do not discuss the bias present in the IRB approval process, the recommendations Flicker et al. suggest offer a concrete way to begin to address some of these concerns.

The alternative language Flicker et al. put forth is meant to redress specific CBPR-related deficiencies that the authors found in the IRB/REB forms that they studied. For example, none asked about community consent. Only three featured questions concerning power imbalances between researchers and participants. Four listed community risks and benefits, but phrased them as broadly “social” rather than as specific to a particular community. Only 5 of the 30 had questions about data dissemination or training for individuals who would have access to sensitive study-related information. Nineteen mentioned protecting vulnerable populations, but those primarily featured lists of “protected populations” recognized in the Code of Federal Regulations, Title 45, Part 46 on protection of human subjects [4]. More than half asked about sample size, but none wanted justification for inclusion or exclusion criteria.

Flicker et al. make the following recommendations for improving the CBPR approval process:

1. IRBs and REBs engaged in reviewing CBPR (and other community-based intervention) grants should be provided with basic training in the principles of CBPR.
2. IRBs and REBs should mandate that CBPR projects seeking ethical review must provide signed terms of reference or memoranda of understanding. These should clearly outline the goals of the project, principles of partnership, decision-making processes, roles and responsibilities of partners, and guidelines for how the partnership will handle and disseminate data.
3. IRBs and REBs should require researchers conducting CBPR to document the process by which key decisions regarding research design were made and how the communities most affected were consulted [5].

They also put forth alternatives for such IRB language as:

Describe how and by whom participants will be approached and recruited. Include copies of any recruiting materials (e.g., letters, advertisements, flyers, telephone scripts). State where participants will be recruited from (e.g., hospital, clinic, school) [6].

They suggest that it could be changed to “What provisions have you put in place to ensure culturally-relevant and appropriate recruitment strategies and materials”[6]?

Another traditional item on an IRB approval form might be “Describe exactly how the research will be carried out” [6], for which the authors suggest the following alternatives:

How will the community be involved in the research? At what levels?
What training or capacity-building opportunities will you build in?

Will the methods used be sensitive and appropriate to various communities (consider literacy issues, language barriers, cultural sensitivities, etc.)? How will you balance scientific rigor and accessibility [6]?

Flicker et al. believe their recommendations will help IRBs and REBs to review CBPR protocols more effectively, remove some of the obstacles facing CBPR researchers in getting IRB or REB approval, and expose other researchers to CBPR themes and concerns by default when they use the same approval process [2].

The authors have made a valuable contribution to the field of CBPR. Changes in form and guidance language that nudge investigators to think about CBPR are worthwhile. More importantly, they continue the discussion concerning how institutional policies and guidance impact CBPR. Taken in that larger context, Flicker et al. build on the earlier conceptual work of Ahmed et al. and begin to give us concrete examples of ways that we can begin to remove barriers to CBPR practice.

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JOURNAL DISCUSSION

Identifying the Challenges in Community-Based Participatory Research Collaboration

Timothy Hotze

Ross LF, Loup A, Nelson RM, et al. The challenges of collaboration for academic and community partners in a research partnership: points to consider. *J Empir Res Hum Res Ethics*. 2010;5(1):19-31.

The modern framework for consent and research is, like much of western philosophy, based upon the individual [1]. Individuals must be informed about the risks and potential benefits of involving themselves in research, and they must consent, individually, to participating in such research. As John Donne wrote, however, “no man is an island” [2], and, in many cases, it is communities as much as individuals that share the risks and benefits of research.

In recent years, an understanding of the importance of engaging communities in research has grown. A widely discussed model for engaging communities is community-based participatory research (CBPR) [3]. This model pairs academic researchers and community members; both partners should have active roles in shaping the research’s aims, design, and implementation.

In theory, CBPR offers benefits to academic researchers, the community involved in the research, and individuals in the community. Researchers may benefit from a better understanding of the community, allowing for better research design. The community can help shape research design and ensure that the actual needs of the community are taken into account. Individuals may have the opportunity to participate in research they would not have known about except through a community organization, and the community may empower individuals to share their ideas and concerns about the research. In many cases, the community may receive direct benefits during the study (e.g., through greater access to health care) and afterward, from greater understanding of cause-effect relationships the study has uncovered, increased attention to preventing or managing problems affecting the community, and so on.

In practice, however, CBPR often differs from this ideal: the demands of academic research, such as including a control group in many study designs, may not be liked or tolerated by some communities, and researchers may not be able (or willing) to accommodate all the needs of the communities they wish to study. Misunderstandings about the goals, benefits, or process of research can strain—or even sever—the relationship between communities and researchers.

Careful planning, with discussions and shared decision making, is therefore essential before engaging in community based research. In “The Challenges of Collaboration for Academic and Community Partners in a Research Partnership,” Ross et al. provide a useful guide to ensuring that the partnership is successful. The authors helpfully organize the article along the lines of an actual research project, from finding a community partner or researcher, developing and conducting the research, and disseminating findings. They have produced a document that is easy both to read and to browse, and it is clear they endeavored to make their discussion useful for both professional academics and prospective community partners.

Ross et al.’s primary advice is that, because trust is essential for a successful partnership, open communication and planning in advance of the start of work is crucial. Their “points to consider” in each section ask important questions that serve as starting points for important discussions between researchers and community partners. Although some of these ideas seem relatively intuitive and straightforward, others might not be at all obvious to researchers or communities embarking on their first CBPR project. For example, in addition to describing the risks to individuals and communities who choose to participate in the research, Ross et al. also ask readers to consider the risks to “non-participating community members” [4].

This highlights an important difference between community-based research and traditional research. It is possible to imagine situations in which individuals who are not eligible or who elect not to participate in the research find their ties to the community weakened or their voice in the community marginalized. Risks such as these, which occur only in community-based research, may be easy to overlook for researchers trained in the more traditional, individual-based human subjects research.

The shift from screening individuals to participate in research to evaluating whether a community is suitable for participation requires a number of additional steps. Ross et al. differentiate between structured communities (they give the example of a church group) and unstructured communities that may need to be structured to some extent prior to conducting research (they give the example of evaluating health care needs of abused women) [5], noting that there may be concerns of legitimacy and agency when a community is fundamentally unstructured.

What Ross and her coauthors do not provide, however, is advice on overcoming many of the challenges they identify. Although an issue can be identified in a bullet point, fully understanding it is more difficult, and crafting a solution can prove to be even more difficult. After reading much of Ross et al.’s advice, the reader is left asking the question “how?”

For example, one of the authors’ points for community consideration in finding an academic research partner is “Does the academic researcher have the skills, experience, and resources necessary for the specific research project?” By definition, community partners lack the academic skills, credentials, and experience to conduct the research themselves. Research on jurists’ interpretation of expert testimony

shows that nontrained members of the public are not able to determine the qualifications of an expert effectively [6]. In this light, it is unclear how the community is supposed to evaluate the credibility of researchers. There is evidence that in such situations, people rely on simple heuristic clues: does the person look, sound, and act the way one would expect a creditable expert to look, sound, and act [7]?

Questions like this highlight the larger issues of power imbalance that may occur between researchers and members of the community. While an equal partnership between researchers and the community is a goal of CBPR [8], it is unclear whether such a goal is actually attainable and whether communities ultimately benefit as much as possible from such research [9]. As Ross et al. note, in many cases, only the researchers are eligible to be principal investigators, given the demands of the grant award process [10]. Even if money is supplied to community organizations, as the authors suggest may be possible, this may understandably be viewed by community participants as money from the researcher-partners given to the community-partner, a “handout” instead of an equal share.

Of the solutions that Ross et al. do propose, some seem made to contain legal liability rather than to foster trust and active partnerships. They propose, for example, documenting agreed-upon terms in a memorandum of understanding or other written document “delimitating the expectations of both parties and documenting the terms of agreement” [11]. Given that researchers are almost certainly more able to envision what activities will actually need to occur through the course of the research, such a document may well conform more to the desires and expectations of the researchers than of the community, which will probably be experiencing the research process for the first time.

In conclusion, although the promise of partnership in CBPR is tantalizing, careful consideration and work are required. Ross and her coauthors helpfully outline many of the concerns that must be addressed, but many of the questions they pose do not have easy answers, and it is unclear how well communities will be able to answer the questions themselves if called upon to become research partners. Even with the careful planning that Ross et al. advocate, CBPR may still fall well short of being a truly equally empowered partnership.

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CLINICAL PEARL

Routine HIV Testing in Older Adults

Lisa K. Fitzpatrick, MD, MPH

In 2006, the Centers for Disease Control and Prevention (CDC) released revised guidelines for HIV testing in health care settings [1]. These guidelines, endorsing routine HIV screening in primary care settings, are aligned with long-established public health principles of timely diagnosis and control of communicable diseases [2]. Routine screening in primary care settings integrates HIV testing with the laboratory tests that are conducted as part of annual physician examinations, including blood glucose, cholesterol, and electrolytes. Despite the release of the CDC recommendations several years ago, nationwide implementation has been sluggish, particularly among older adults who are not perceived to be at risk for HIV [3, 4]. Consequently, over the last few years, the CDC has reported an increase in new HIV diagnoses in persons over 50 years of age, with more than 15 percent of all new diagnoses falling in this age group [3]. The emerging HIV epidemic among older adults warrants urgent clinical and public health attention.

Clinical Case Scenario

In 2009, a 66-year-old widow was referred for infectious diseases consultation by a primary care physician. The patient was newly diagnosed with HIV, and her CD4 count was less than 200. She had AIDS. Despite being in the physician's care for hypertension and diabetes for over 10 years, she had never been tested for HIV, nor had her physician considered her to be at risk for it. The diagnosis was a coincidental discovery during her hospitalization for persistent diarrhea. Upon presentation for HIV care and treatment, she asked several questions about her new diagnosis that suggested she had little knowledge about HIV infection or how it was transmitted. Furthermore, she reported 10 years of celibacy and was bewildered by the diagnosis. She asked why, in all of her interactions with health care professionals over the years, none had ever discussed HIV.

Lessons Learned from Missed Opportunities

Unfortunately, scenarios like this are increasingly common and warrant the attention of health care professionals for several reasons. First, many physicians do not consider older adults to be at risk for HIV infection. As a result, many older persons are diagnosed late in the disease. Meanwhile, data show that many older persons have sexual risk factors for HIV. A study conducted in 2004 to assess the prevalence of sexual behavior among older adults found that 73 percent of persons aged 57-64 reported having engaged in sexual activity during the previous year. Among those aged 65-74, 53 percent reported having engaged in sexual activity, as did 26 percent

of those aged 75 to 85 [5]. Therefore, HIV testing and prevention counseling should be offered to older adults just as it is to younger patients.

Second, opportunities for diagnosing HIV in older adults may be missed due to misinterpretation of signs and symptoms that are common among the aging. The HIV status of the patient in the case scenario was identified during a workup for diarrhea. Many older adults present with signs of normal aging such as fatigue, mental confusion, and weight loss—symptoms that may also signal HIV infection. Failing to consider HIV in the differential diagnosis for aging patients leads to increased HIV morbidity and mortality, particularly since many older patients already suffer from preexisting conditions like diabetes, heart disease, and renal insufficiency. The delay in diagnosis and treatment of HIV in older adults has led to poorer outcomes, including lower baseline CD4 counts, decreased time to onset of AIDS, and increased mortality from AIDS-related illness [6, 7].

Third, data show that health professionals are often uncomfortable discussing a patient's sexual history, discomfort that is likely to be exacerbated in older patients and that can lead to missed opportunities for diagnosis. In a sexuality study among persons over 50 years of age, only 38 and 22 percent of men and women, respectively, reported having a physician-initiated conversation about sexuality [8].

Anecdotally, medical students have reported a lack of clinical instruction on how to approach taking a sexual history. Although the subject may be somewhat uncomfortable, particularly when the clinician is younger and the patient is older, the sexual history is essential to good medical care and can provide important clues about a patient's risk for HIV infection. To avoid patient discomfort and awkwardness when obtaining a sexual history, physicians should consider inserting the sexual history seamlessly between nonsensitive sections of the social history such as inquiries about employment and pets or recent travel. Finding a comfortable style for obtaining a sexual history is the most critical element to eliciting such sensitive information and is necessary for identifying older patients who can benefit from additional screening and prevention messages.

Finally, as illustrated in the case scenario, HIV literacy is low among older adults, and health care professionals should serve as an HIV information resource. A study assessing HIV prevention among older adults revealed that HIV knowledge and condom usage were inadequate in that group [9, 10]. Given these knowledge gaps, older adults are unlikely to utilize condoms during sexual activity or purposefully seek HIV testing.

Avoiding Missed Diagnoses in Older Adults

Given the need for early identification of HIV infection among older patients, it is imperative that physicians and other health care professionals adopt routine HIV screening as a standard of care. As outlined by CDC, routine screening can accomplish several goals:

Elimination of HIV-testing stigma. If testing is adopted as the standard of care, older patients will not feel stigmatized by it.

Avoidance of missed opportunities for identifying HIV infection in early disease stage. Routine screening will eliminate physician guesswork in deciding when HIV testing is warranted.

Reducing the U.S. AIDS burden. Earlier identification and linkage to care leads to earlier treatment and avoidance of AIDS.

Implementation of routine HIV screening in the health care setting is often perceived as difficult, cumbersome, and challenging, but it can be straightforward and logistically feasible. Two concrete suggestions for implementing routine screening are adding HIV consent to the general informed consent form and, after telling the patient, adding an HIV ELISA to the panel of routine tests conducted for general care. Strategies like this can help eliminate missed HIV diagnoses in older persons.

Conclusion

Implementation of the revised CDC HIV-testing guidelines in adults is imperative to improve early identification and reduction of HIV morbidity in older adults. Although older adults may have low HIV literacy and may not perceive themselves to be at risk for HIV infection, health care professionals must exercise the clinical leadership required to diagnose HIV infection early and to educate older adults about their risk for HIV infection. Through early diagnosis and education, it is possible to reduce substantially the burden of AIDS in older adults and possibly even to eliminate AIDS diagnoses among older adults altogether.

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HEALTH LAW

Genetic Research among the Havasupai: A Cautionary Tale

Robyn L. Sterling, JD, MPH

Imagine that you donated a bit of blood to a researcher whom you believed intended to identify a genetic link to a disease ravaging your community, only to discover years later not only that you had been misled, but that other researchers were mining your DNA for reasons that were never disclosed to you. What would you do? This was the case for the Havasupai Tribe in Arizona, who learned that researchers at Arizona State University (ASU) had gathered blood samples from them to search for a link to diabetes but used the samples to look for other diseases and genetic markers, thereby violating the basic tenets of human subject research. To determine where the breakdown between the Havasupai Tribe and ASU occurred, let's look at community-based participatory research and its underlying principles of informed consent.

Background

The Agency for Healthcare Research and Quality (AHRQ) defines community-based participatory research (CBPR) as a “collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change” [1]. CBPR, as AHRQ describes it, further entails shared decision-making power and mutual ownership between the community and the researchers. Over time, researchers have come to recognize that, with community commitment, they could work effectively to assist in identifying and resolving health care disparities [2].

Topics for community studies have ranged from asthma in urban populations to genetic propensities to develop various types of cancer. Well-known CBPR studies include those that helped identify the BRCA1 gene prevalence in the Ashkenazi Jewish population and the sickle cell trait among African Americans. Certain fundamental principles apply in conducting CBPR, regardless of the group in question. It is vital that a researcher respect the community and its values and beliefs and follow the principles of human subject research, namely, obtaining informed consent from the community. Not only can failure to adhere to informed consent protocols be devastating to a community, it can permanently damage the credibility of a researcher or institution.

The Principle of Informed Consent

Informed consent has been a point of debate and concern since its origin in the post-World War II Nuremberg Code, which is a set of guidelines drafted to ensure that harms to humanity like those in Nazi “medical” experiments would never occur again in the name of science [3]. Informed consent is achieved when a competent individual agrees to participate in a study or procedure after having expressed clear understanding of all material facts related to the activity in question. These facts are provided by the researchers and empower the individual to make an informed choice, in full recognition of the nature and consequences of the decision.

The Tuskegee Syphilis Study, which began in 1932, involved approximately 400 African American men infected with syphilis. The U.S. Public Health Service tracked these men for roughly 40 years without providing them with a diagnosis of their disease or any opportunity for treatment [4]. This was a direct violation of informed consent principles and the antithesis of how CBPR should be performed. As a result of their lack of treatment and lack of knowledge, hundreds of the men and their families lost their lives to a treatable disease.

Congress responded with the National Research Act in 1974, which created the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research [5]. In 1979, this commission published the Belmont Report to identify the minimum ethical principles required for human subject research, which included informed consent as a basic tenet [6].

The federal government did not stop with the Belmont Report. In 1991, the U.S. Department of Health and Human Services published the Common Rule, which mandated that researchers obtain informed consent before engaging in most types of human subject testing [7]. The elements of informed consent have been codified within the Common Rule to include: a statement that the study involves research; the purpose of the research, the duration of the research and the procedures that will be followed, a description of any potential benefits to the subject or to others which may result from the research, a statement describing how the confidentiality of the subject will be maintained, and an explanation of whom to contact for answers about the research and research subjects’ rights [8]. These elements are vital to ensuring that an individual can truly make an informed choice.

Obtaining informed consent from a community for CBPR can be difficult, time-consuming, and fraught with challenges. Sometimes, for example, an individual is not only consenting on his or her own behalf but must secure the approval of a community leader before participating in any type of study. Therefore, a researcher must take the time to establish a trusting relationship between herself and the community and its leaders, which includes following through on promises and maintaining contact with the community [9]. A community leader can be the head of a Native American tribe, the head of a church or synagogue, a spokesperson for an informal community of individuals with a common interest, and so on. Lines of

communication must remain open to these leaders and the community as a whole to ensure dialogue and participation throughout the study and the relationship.

Perhaps the most crucial element is making sure that the community is truly informed about the full extent of the research and consents to it. The Havasupai Tribe's claim against Arizona State University illustrates what can happen when researchers—either intentionally or through negligence—do not make the full extent of their research goals known.

The Havasupai Tribe CBPR Experience

In 1989, members of the small tribe of approximately 650 poverty-stricken people approached ASU anthropology professor John Martin, with whom the tribe had a preexisting and trusting relationship [10], seeking to learn why the incidence of diabetes within their community was increasing. Genetic links to diabetes had been identified in another tribe, and, if a similar gene could be located among the Havasupai, it might provide a tool for addressing risk factors. Professor Martin approached a colleague, Therese Markow, a geneticist at ASU, to assist in the study. Dr. Markow's previous work had touched upon other diseases, specifically schizophrenia, and she wished to expand the study to include mental disorders [11]. Professor Martin is said to have responded that he did not believe there would be interest in Dr. Markow's research on the part of the tribe, but Dr. Markow continued with her mental disorder research based on the samples provided by the tribe [11].

Approximately 100 tribal members signed a broad consent document to “study the causes of behavioral/medical disorders” [12]. Most of them had not completed high school, and, for many, English was a second language [12]. All of the tribe members believed that they were donating blood solely for the purpose of looking for a link to diabetes to improve the health in their community [13]. ASU researchers determined that the genetic link to diabetes found in the other tribe did not exist among the Havasupai but continued their research into medical disorders without seeking additional consent from the tribe. Other ASU researchers also utilized the Havasupai samples for their work and published papers about inbreeding, alcoholism, and the origin and migration of the tribe from Asia. Although the hard data published in these studies may have been accurate, the studies violated informed consent, and theories about the tribe's origin conflicted with their core beliefs.

The complaint in the case of *Havasupai Tribe vs. the Arizona Board of Regents* listed six charges that included lack of informed consent, violation of civil rights, and intentional or negligent infliction of emotional distress. ASU paid for a private investigation to keep the suit out of the courts, and, after seven years of litigation, 41 members of the Havasupai Tribe settled in April 2010. ASU is reported to have spent upwards of \$1.7 million defending itself against the allegations. The terms of the settlement were a payment of \$700,000, the return of the blood samples, and additional assistance including scholarships and help in obtaining federal funding for a health clinic for the impoverished tribe [12]. The Havasupai tribe's experience demonstrates the extensive harm that can be done to a community—some of it

irreparable—through violation of informed consent. The research subjects were not adequately informed about how their DNA would be used at the university, and this significantly impacted the integrity of their community and their trust of outsiders.

The April 2010 settlement initiates a healing period for the tribe, yet ASU's reputation—along with that of the researchers—seems to have been permanently undermined by the informed consent violation. Some tribes still refuse to work with ASU [12]. This situation could have been avoided if the informed consent documents had been clear, and if information had been properly and patiently conveyed in full to the tribe. Moreover, those looking to engage in further study of the original samples should have gone back to the community to obtain new informed consent for the additional research. It appears unlikely that the Havasupai would have consented to research related to schizophrenia and other disorders, which would have saved the tribe much of the emotional distress they experienced. What can be gleaned from this glaring example of research gone wrong is that, by failing to follow proper protocols and regulations, a researcher engaging in CBPR may inflict permanent harm on the participating community and chill future research among disadvantaged populations.

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POLICY FORUM

Community-Based Participatory Research and the Academic System of Rewards

Nicolette I. Teufel-Shone, PhD

Science...seems an attempt to force nature into the preformed and relatively inflexible box that the paradigm supplies. No part of the aim of normal science is to call forth new sorts of phenomena; indeed those that will not fit the box are often not seen at all. Nor do scientists normally aim to invent new theories, and they are often intolerant of those invented by others.

Thomas S. Kuhn [1]

The National Institute of Health (NIH), the Centers for Disease Control and Prevention (CDC), the Robert Wood Johnson Foundation (RWJF), and other primary funders of health-related research have identified community-based participatory research (CBPR) as essential to deepening our scientific knowledge of health promotion and disease prevention and reducing racial and ethnic health disparities [2-5]. The Institute of Medicine (IOM) has named CBPR as one of eight competencies for all health professional students [6]. Yet, as an expanding cohort of junior university-based CBP researchers proceed through the academic system—specifically through the promotion and tenure process—many continue to be reviewed using the standards developed for non-CBP researchers. As stated in Calleson et al.’s seminal article recommending change, “If we want faculty to be involved in communities but reward them for other activities, we are our own worst enemies” [7].

The Nature of CBPR

CBPR’s guiding principle of engaging community and university partners equitably in all stages of research yields a process quite distinct from traditional research led by one or a team of university-based principal investigators (PIs). Table 1 offers a brief look at how CBPR differs from traditional research.

Table 1: Comparison of CBPR and traditional research

	Traditional Research	CBPR
Research ideas and hypotheses	Generated by university-based researchers	Generated by community-university research team
Goal	Knowledge	Social change
Research focus	Disease and health outcomes	Interplay of socio-cultural context and health behaviors
Background research	Peer-reviewed sources	Combination of information from community experiences

		and peer-reviewed sources
Recipient of external funding	University	Community and university share funding
Guiding framework	Logical model	Iterative collaborative process
Leadership	University-based PI or co-PIs	Community-university co-PIs
Length of research	Length of funding periods	During and between funding periods
Indirect cost rate, reflecting primary research site	University rate	Community rate or off-campus university rate
Essential skills for PIs	Leadership and management	Collaboration and relationship building
Decision-making method	Hierarchical	Consensus
Definition of success	Assessed by academic peers and measured through peer-reviewed publications, papers presented, and grants received	Assessed by the community and measured through sustained change in social behaviors and policies that impact health

The Nature of the Academic System of Rewards

Weiser et al. point out that “a university’s values are most clearly described by its promotion and tenure policy and by the criteria used to evaluate faculty members” [8]. Calleson et al. conclude that “most academic health centers and health professions schools do not truly value community partnerships and the community involvement of their faculty as central to achieving their institutional missions” [7]. These statements refer to conventional institutions that base success upon three criteria: (1) evidence of peer recognition of excellence in research/scholarly activity; (2) documentation that teaching is of high quality; and (3) documentation of significant service [9-11]. The parameters of the first criterion, designed to reflect independent scholarship, are perhaps the most incongruous with CBPR. By tradition, acceptable evidence of the first criterion has been peer-reviewed publications, extramural funding, and letters of evaluation from peers at other institutions.

In evaluating a faculty member’s publication record, the number of publications per year, position of authorship (with first or last carrying the greatest weight), and journal type influence the review. The ranking of journals is based on a system internal to academia. Journals are ranked by the Healthcare and Science division of Thomson Reuters, an information firm, using a systematic appraisal of research influence as measured by an Impact Factor and Immediacy Index [12]. Impact and immediacy refer to frequency with which an article is cited in other academic contexts and how close to the time of its publication those citations occurred. The “real world” effect of the research findings or dissemination in nonacademic arenas has no effect on the article’s “impact and immediacy” in the index. First-tier

journals, the most valued, publish articles that are cited often and soon after publication by the greatest number of academic researchers in a field [12].

In the evaluation of external funding and outside letters of support, the review is again somewhat internal to the academic system. Source of funding, amount and period of support, and, in some cases, the amount of support provided for the PI and other university personnel are assessed. Outside letters of recommendation from national and international leaders based in research-intensive institutions are collected to “speak directly to the quality and impact of a candidate’s work” [13]. Letters from community leaders and policy makers who may use the candidate’s work to guide decision making and allocate funds are not solicited for inclusion in a traditional promotion and tenure package.

Are the Two Systems Compatible?

In the current, traditional environment, these approaches are not compatible. Independent scholarship and recognition by the academic community are not the primary goals of CBPR. Its emphasis is less on individual leadership and more on facilitation and synergy. Successful CBPR effectively weaves together the knowledge and skills of all partners in the interest of understanding the production of health and instituting a new way of behaving socially, politically, or economically to reduce health disparity. Lessons learned by a specific partnership may be relevant to others but are not intended to be directly transferable. The initial value of research activity is reflected in the community partner’s experience with the institutional, policy, or social changes. Regional, national, and even international dissemination is important for advancing the science of CBPR and health equity, but is not the initial measure of success.

Accomplishments of a CBP researcher do not lend themselves to clear reporting within a traditional promotion and tenure framework. Documentation guidelines do not ask the candidate to report the years that a partnership has been active, only the years of funded research; they do not ask for a description of the invitations extended by other communities impressed with change in a community that partnered with the CBP researcher, only the number of peer-reviewed publications that emerged from the research; they do not solicit input from community leaders or health care professionals who worked with the candidate, but invite evaluation from academic leaders who have no familiarity with the community’s experience.

The paucity of tenured CBP researchers in academic institutions creates a lack of senior leadership to advocate for administrative and policy change, suggest faculty development activities commensurate with successful CBPR, and serve as role models and appropriate mentors for junior CBPR faculty. Junior researchers are often advised by well-meaning, non-CBPR senior faculty to reserve their CBPR aspirations until they have received tenure. This advice is driven by the observation that CBPR does not produce peer-reviewed publications at the rate expected by most academic institutions and can negatively affect the tenure and promotion process [14].

CBP researchers are challenged to think strategically about ways to convey their accomplishments and simultaneously educate their non-CBPR peers about the nature of their research. This process is not required of traditional researchers and seems particularly arduous for junior faculty already engaged in research that is recognized as time-intensive [3, 5, 7].

But the tide is changing. Some research-intensive institutions have changed “business as usual” and supported new tenure and promotion standards for the review of community-engaged scholars [9, 14-18]. Several articles describe activities that CBPR-supportive institutions weigh as comparable to more traditional criteria and provide additional suggestions for review [15-18]. In this vein, documentation from communities and academic peers is weighed equally. After all, are not health professionals accountable to their constituents and partners as well as their academic peers?

Some institutions have established a two-track system that allows a different set of criteria to be used in the evaluation of CBP researchers [16]. Given the entrenchment of the traditional approach, will a new path defined by the undervalued process of community engagement truly be viewed as equivalent to the more traditional road? Will CBP researchers who proceed successfully through this second track be considered leaders worthy to assume positions such as regents’ professors, deans, provosts, and even university presidents in the later stages of their careers, or will they always be viewed as a less rigorously evaluated pool of faculty, i.e., “not real scientists”?

Progress is slow. Promising researchers are choosing not to remain on a tenure track and in some cases are leaving the academic system [19]. CBPR is coming of age. To stay on the edge of discovery and retain innovative researchers, academia must accept the challenge of dramatically revising the system of rewards involving all feeder and seminal processes, e.g., mentoring, promotion and tenure requirements, and composition of review committees. The individual, often junior, CBP researcher cannot effect these changes. As increasing numbers of universities offer CBPR courses and the impact of CBPR is recognized, the academic system of rewards needs to adapt to encourage an impassioned generation of scientists to make a difference.

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MEDICINE AND SOCIETY

“Vulnerable” Populations—Medicine, Race, and Presumptions of Identity

Karla F.C. Holloway, PhD, MLS

At the beginning of the twentieth century, renowned sociologist William E. B. Du Bois warned that “the problem of the twentieth century” would be “the problem of the color line” [1]. I suspect that Du Bois would not have imagined that this color line would be as enigmatic and troubling in the twenty-first century. But the fact is that today’s issues of race and identity reveal an arguably more complicated terrain. To illustrate this point, consider the background of the following patients [2].

Ms. A’s father is Nigerian and her mother is British.

Ms. B’s mother and father are both from Jamaica. She has lived in the United States since birth.

Ms. C’s parents were both born in the United States. Her father is from Detroit’s inner-city and her mother is white.

Ms. D’s parents were born in Ghana and South Africa.

Ms. E, who has curly blond hair, fair skin and green eyes, has checked the box for “black or African-American” on her medical history form. She was adopted at birth.

In fact, each of these patients has checked that same box—“black or African American”—on their patient history forms. What does this tell us?

The quick answer is that it tells us not much at all about the patient—but a whole lot about whomever provided the box. Just the quick background sketch I provided for patients 1-5 indicates how different they are. In fact, the receptionist who made the appointment for the woman with Jamaican parents was surprised to see a woman with brown skin report at the scheduled time. “On the phone, you sounded like you were British,” she told her as she gave her a clipboard with the new patient information form attached to it. In the receptionist’s racial imaginary, being (or sounding) British is a stand-in for being white.

The receptionist is not alone. When you read about the first woman (the one with the Nigerian father and the British mother) did you make a presumption about the race of the British mother that would coincide with the receptionist’s? Did the third patient’s “inner-city Detroit” father signal a particular race for you? If so, you’re not alone. For the majority of Americans, “urban” (or “inner-city”) is a synonym for black or African American. “Suburban” is a synonym for white. Geography matters. Before we leave this example, did it occur to you that the fourth woman’s South African parent might be white (something we tend to ignore when we imagine “African” ancestry)?

These examples indicate the ways in which U.S. residents are primed to make certain presumptions regarding race. We've given race its substance and assured its viability despite its growing complication as a coherent category of identity. There's little doubt of medicine's interest in sustaining these racial designations. Patient history questionnaires betray this preoccupation. But what is it that we learn from a patient's response? Is it worth the sustained stereotyping that comes from some people being assigned to a community and others not?

Our research and our practices both confuse and conflate the many social referents of the word "race." We commit this error most frequently when we tolerate the notion that prompts our assigning someone membership in an "African American community." It is an affiliation that suggests that being "black or African American" places you into immediate and reasonable consonance with any other black person in this country. Our habit of assigning community also suggests that phenotype reveals something about biology in a reliable and consistent enough manner to make that categorical assessment have standing equal to other factors like weight, dietary habits, smoking history, and whether or not you had rheumatic fever as a child.

The black folk whose souls Du Bois worried over in 1903 had a peculiar history of visibility and vulnerability. It is a history replete with narratives about medical care of lesser quality and exploitation sutured to institutionalized racial biases and stereotypes. When contemporary medicine takes up the category of race as a biologic rather than a social indicator, it ignores the complexity that is resident in "African American communities." A community-based medicine or research ethic cannot escape this history of identity and vulnerability and the significant variables that accompany the experience of race. This is not an occasion when new and good intentions erase the impact of past bad acts. Language has a habit of entanglement.

"Vulnerable" patient populations are not an invention of bioethicists in search of a subject. When bioethicists refer to vulnerable populations these persons might be minorities, women, children, the elderly, the imprisoned or other institutionalized persons. We sometimes forget that the source of their vulnerability is not intrinsic. It is decidedly extrinsic. They are, as the title of this essay indicates, vulnerable to patterns of institutionalized bias. Categorical vulnerability is a consequence of medical research and medical practices that have exposed persons to bad acts because of a guiding presumption about the value of their identities [3]. The labeling does not develop a neutrality simply because we bring it to a different setting and a new era. We take ourselves wherever we go. The assignation of community and color began as a way to distinguish rights and assign moral value. That history is not dissoluble simply because a contemporary society accepts this labeling as benign—just one among several options. There is a lived history in our words.

The simplest way to make this plain is to ask someone to point you in the direction of the white community. It is a reasonable bet that your request will be met with some degree of puzzlement. But if you asked to be directed to the black or Latino

communities, your chances are pretty good that you'll get an easy answer to the inquiry.

The ability or the inability to locate the “white community” precisely underscores the social construction of the inquiry and its answer. Black and brown folks are visible in ways that renders whiteness both invisible and inconsequential. In fact, the privilege of whiteness has made the contemporary complexity of race and ethnicity in the United States persistently vulnerable to the practices of history [4]. Social and biopolitical circumstances are the substance from which determinations about biologies of body and blood are determined. We forget the association of society to science and recall the science. This is a flawed way in which to make determinations about patient outcomes and patient profiles. In an age where we still hope there are genomic indicators that can point us toward individualized patient care, there is little reason to depend on a racially categorized community (that includes only some of us) before making health-related decisions about anybody. But the social is a powerful motivator, and the language with which we have come to designate certain populations is a familiarity that is difficult to disregard.

Given the opening example of five patients, what other than a professional's ease and want of efficiency makes the “African American community” a viable category? Perhaps a more useful question is how physicians might deliver better patient care and develop and practice more attentive listening strategies if the artifice of a community membership didn't begin writing a patient's narrative before any questions had been asked or answered. This perspective constructs a research ethic that begins with an affirmation of the body biologic. It returns a professional authority to the physician, and abjures practices that elevate race in ways that might obscure critical differences. It is a perspective that restores a patient's autonomous standing as a person rather than a racial representative—a member of someone's idea(l) of a community.

A final example might be helpful. When the head of an administrative search committee was asked how her committee was assuring a diverse candidate pool, she pointed out that there were two black faculty representatives on the committee for the “African American community.” This kind of nonsense needs a blunt and unambiguous response. Diversity should be the responsibility of the entire committee, not something turned over to the black folks in the room. The categorical presumptions of a coherent and even an insular “African American community” encourage this kind of simple-mindedness and lack of accountability. It illustrates the harm in producing a community as a commodity.

It is antithetical to reach toward a science that will bring us closer to the goal of individualized medicine with a research paradigm that begins with “community”-based categories. Certainly and without argument there are occasions when ethnicity and race will matter. Discrimination produces stress. Stress can contribute to hypertensive disease. Black folks are vulnerable to discrimination. However, in an ideal research paradigm, this relational outcome would be the product of research

and investigation that discovers the relationship rather than with a hypothesis that instantiates the difference. With this kind of shift in perspective, we might end up with research practices that bring us closer to the achievement of individualized medicine where rigorous science and credible social science drive the questions. This seems a goal worthy of a *professional* community's collective effort.

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