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Human Genetics, Environment, and Communities of Color: Ethical and Social Implications

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A conference titled “Human Genetics, Environment, and Communities of Color: Ethical and Social Implications” and a workshop symposium titled “Human Genetics and Environmental Justice” were held by West Harlem Environmental Action, Inc., with cosponsorship by the National Institute of Environmental Health Sciences (NIEHS), the Community Outreach and Education Program of the NIEHS P30 Center for Environmental Health at the Mailman School of Public Health at Columbia University, New York, and the U.S. Environmental Protection Agency. The conference and symposium took place at Columbia University in New York City on 4–5 February 2002. Expert panels composed of public health practitioners, genetic researchers, ethicists, lawyers, social scientists, and community organizations were assembled to explore how genetic research will affect communities of color, specifically in environmental health research. The goal of the conference was to educate participants on the science and ethics of genetic research and to explore the potential benefits and pitfalls of genetic research vis-à-vis new trends in environmental health research, specifically with reference to communities of color. The goal of the symposium was to discuss the major perceptions and concerns for community-based environmental justice advocates and other communities of color regarding environmental health genetic research. The conference and symposium drew more than 300 participants and articulated important perspectives on the opportunities and challenges for environmental justice advocates and other communities of color posed by rapid advances in environmental health genetic research and toxicogenomics. **Key words:** communities of color; community-based research; environmental genome project; environmental justice; ethical, legal, and social implications (ELSI); ethics; human genetic research; toxicogenomics. *Environ Health Perspect* 112:740–745 (2004). doi:10.1289/ehp.6731 available via <http://dx.doi.org/> [Online 29 January 2004]

Emerging trends in genetic research have the potential to transform the nature of environmental health and risk assessment. The Environmental Genome Project (EGP) of the National Institute of Environmental Health Sciences (NIEHS) seeks to determine the variation of environmental response genes among individuals, which determine susceptibility to environmentally related diseases (NIEHS 2003). The potential of the EGP includes more aggressive disease prevention through earlier detection of disease warning signs, better protection of sensitive subgroups, and no less than a fundamental transformation of risk assessment of chemicals (Wakefield 2002). The EGP also promises to revolutionize pharmacology by helping pharmaceutical companies identify drug-sensitive subpopulations and design drugs that are matched to particular genotypes. The toxicogenomics research consortium of the NIEHS seeks to understand how the entire genome is involved in biologic responses of organisms exposed to environmental toxicants or stressors (Schmidt 2002). Toxicogenomics promises to use new methods and technologies to obtain a more fundamental understanding of chemical- and drug-induced disease processes. Toxicogenomics may also help guide federal agencies and legislators in developing guidelines and laws that regulate the

concentrations of various chemicals in the environment (Schmidt 2002).

As environmental health genetic research continues to mature, public concern about the ethical, legal, and social implications (ELSI) of this research and its applications is escalating. Attention to ELSI is a common thread underlying all fields of genetic research. The ELSI Program of the Human Genome Project—an endeavor of the National Human Genome Research Institute, which completed sequencing the full human genome in April 2003—focused primarily on privacy and fairness in the use and interpretation of genetic information and on clinical integration of genetic technologies, avoiding genetic determinism and group stigmatization (the reduction of complex biologic functions to simplistic genetic explanations) (NHGRI 2003). These concerns are not specific to the United States; popular movements in Europe and in the Third World have also raised these issues. However, a subset of concerns related to human genetic research has focused on the unique challenges faced by people of color in the United States, situated within a historical context of biomedical racism such as the eugenics movement and the notorious Tuskegee syphilis study (Bradby 1996; Jones 1981; Lee et al. 2001). Eugenics was a pseudoscientific movement of

the 19th and early 20th centuries that used the language of universal science in an attempt to improve the human race through breeding, which in fact was extremely destructive to particular vulnerable subpopulations, the poor, racial minorities, criminals, and the mentally and physically disabled through sterilization and marriage laws (Gould 1981; Kevles 1985; King 1992; Selden 1999). Between 1932 and 1972, the U.S. Public Health Service conducted an experiment in Alabama on 399 poor black men, most of whom were illiterate sharecroppers, in the late stages of syphilis. The men were never told about or treated for their disease and were left to suffer the effects of tertiary syphilis—including tumors, heart disease, paralysis, blindness, insanity, and death. They were told only that they were being treated for “bad blood.” In 1997, President Clinton offered an apology to the eight remaining survivors of the study (Clinton 1997).

Despite the often-repeated fact that there is no biologic or genetic basis for racial categorization, population-based genetic research specific to communities of color—wherein DNA samples from individuals belonging to a socially identifiable racial or ethnic group are collected and labeled as such—continues to take place, raising questions and confusion

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about whether this research undermines that assertion.

To date there has been relatively little inquiry into the potential ELSI impacts of genetic research specific to environmental health, particularly on its impacts for communities of color (for overviews of the NIEHS's ELSI work, see NIEHS 2003; Sharp and Barrett 2000). At the intersection of genetic research, environmental health, and communities of color lies a complex set of questions regarding the environmental justice (EJ) implications of environmental health genetic research (Sze et al. 2002). The EJ movement strives to eliminate racial and economic disparities in environmental health by reducing the disproportionate burden of pollution and poor environmental quality borne by low-income communities and communities of color (Shepard et al 2002). Communities of color and low-income communities across the nation are more likely than white and middle-class communities to face such environmental hazards (Lee 1987). In 1991, the First National People of Color Environmental Leadership Summit was held in Washington, DC, where more than 600 environmental activists and people of color gathered to discuss their grassroots struggles for EJ and produced 17 "Principles of Environmental Justice" (First National People of Color Environmental Leadership Summit 1991). These principles include a call to "the strict enforcement of the principles of informed consent," as well as "the right to participate as equal partners at every level of decision-making" (EJ Summit 1991).

Conference Objectives

In the spirit of these principles, West Harlem Environmental Action, Inc. (WE ACT), a nationally prominent EJ organization, hosted a national conference titled "Human Genetics, Environment, and Communities of Color: Ethical and Social Implications" and a subsequent symposium titled "Human Genetics and Environmental Justice," held in New York City on 4–5 February 2002. The conference and symposium were cosponsored by the NIEHS, the NIEHS Center for Environmental Health at the Mailman School of Public Health of Columbia University, New York, and the U.S. Environmental Protection Agency. More than 300 participants, half of whom were community activists of color, from 34 states and Puerto Rico attended the conference. These participants came together to explore potential benefits and pitfalls of genetic research for communities of color, with an emphasis on new trends in environmental health research.

After the conference, the Human Genetics and Environmental Justice symposium was held to begin a dialogue among EJ advocates regarding their perceptions, concerns, and hopes for the impact of genetic research on

environmental health in communities of color. Seventy-five participants, primarily community-based EJ leaders, attended to discuss how they could be informed and prepared to handle both the challenges and opportunities for environmental health and justice posed by emerging genetic technologies and knowledge generated from new research.

This meeting report provides a summary of key themes that emerged during the conference and the symposium.

Conference Themes

Race and genetics. Human genetic research holds many implications for the concept of race and the struggles against racism in our society, rooted in the biologic versus social framings of "race." During his conference keynote, Troy Duster, then President of the American Sociological Association, contrasted the ways in which "race" is interpreted scientifically as opposed to how it is constructed socially. He noted that the Human Genome Project has provided further support for scientists who seek to abandon the concept of "race" altogether, in the hope of divorcing the future of scientific research from some of its more sordid historical chapters, such as eugenics. But the removal of the concept of "race" from the scientific arena, he noted, does not automatically carry over to the policy applications of science (Duster 1990; Goodman 2002).

Conference participants concurred, noting the importance of distinguishing between inaccurate biologic and genetic framings of race, and the lived reality of race and racism as social constructs (Lee et al. 2001). This distinction becomes especially important for researchers conducting research related to socially identifiable population groups. Consideration of the media's and policy makers' interpretations of research findings related to "race" and ethnicity in genetic research is crucial to avert harm and maximize benefits for communities of color. A basic tenet of the EJ movement is that outcomes matter more than intent. This principle, when applied by researchers and policy makers, can provide a useful way to evaluate the risks and benefits of research for communities of color by asking "What are some of the potential (unintended) outcomes that this research might lead to?"

Participants in the EJ symposium noted some puzzling environmental health implications in the findings of genetics scientists regarding "race" and genetics, related to the conflation of population groups with "race." In his symposium presentation, molecular biologist Seymour Garte (University of Medicine and Dentistry of New Jersey, Piscataway, NJ) noted that although 99.9% of human genes do not change much over generations, the rest are highly variable because of heavy selection pressure from environmental

factors such as climate, altitude, humidity, diet, and disease. Race is not a genetic marker, Garte noted, but for some human genes there are racial differences in average allele frequency: for example, skin color, body/face appearance, disease resistance, and metabolism. Garte described a "racial genetics paradox": Although there is more variation within races than between races for most genes related to environmental exposures, some differences in allele frequency can lead to potential differences in environmental susceptibilities between individuals from different socially identifiable racial or ethnic groups (Garte 2002). Garte argued that the racial genetic paradox could be resolved by research into the role of natural selection pressure on population-specific differences in allele frequency. Although populations can overlap with racial categories, they are not the same thing, and this reality needs to be clear through every step of research, public policy, and public communications.

Gene–environment interactions in disease causation. If research on gene–environment interactions is to prevent disease and improve health, the complexity of this interaction must be communicated effectively to the public and particularly to the media and policy makers. A long-standing critique of the Human Genome Project and related genetic research has been that such research inadvertently contributes to genetic reductionism in media and policy arenas. Genetic reductionism is the oversimplification of the complexity of human biology and health to a function primarily of genes. In discussing the tension between environmental exposure and genetic susceptibility with respect to environmental risk and disease causation, several conference speakers expressed concern that research into disease causation, and the policy applications of that research, would focus disproportionately on genetic factors with inadequate emphasis on environmental factors, particularly those associated with environmental exposures.

Rapid advances in genetic technologies and research applications could exacerbate rather than mitigate disparities in health and health care. Debra Harry of the Indigenous Peoples Council on Biocolonialism (Wadsworth, NV) noted that the health conditions most commonly suffered by indigenous peoples today are complex conditions such as type 2 diabetes. Many of these conditions, aggravated by economic poverty, lack of infrastructure, and contaminated environments, are often preventable. Harry argued that the most optimal use of public funding to improve the health of these communities is in preventive care and increasing access to known treatments, rather than the applications of genetic research and emerging technologies. She also noted that medicines today are designed for profitable markets and

that it is unlikely that new drugs or treatments would be developed to meet the needs of poor or underserved communities.

Environmental health genetics: implications for regulation and risk assessment. At the EJ symposium, Jose Morales of Public Interest Biotechnology (New York, NY) noted that research being done on exposure, toxicity, and susceptibility would change the overall understanding of risk. This potential change raises numerous complex concerns regarding the social context in which research is taking place, and the potentially negative impacts such research may have on communities of color regardless of the intent of researchers.

One fear is that insurers or employers may use genetic information to deny coverage or employment. Equal Employment Opportunity Commissioner (EEOC) Paul Steven Miller (Washington, DC) described one such incident at the conference. In 2001 the EEOC (Washington, DC) accused Burlington Northern Santa Fe Railroad of violating the Americans with Disabilities Act (EEOC 2001a) by submitting its employees to genetic testing for carpal-tunnel syndrome without the workers' knowledge, despite the inaccuracy of such a genetic "test." The workers' union accused the railroad of attempting to avoid paying compensatory damages to people injured with carpal-tunnel syndrome. Ultimately, the railroad settled the lawsuit by agreeing to neither directly nor indirectly request or require genetic tests, and to publicly advocate for federal legislation prohibiting genetic testing (EEOC 2001b). Conference participants noted that genetic discrimination in the workplace is expressed not just through genetic testing. Potential findings that socially identifiable ethnic groups carry a higher frequency of an allele potentially contributing to greater susceptibility to a particular exposure found in the workplace may lead to attempts by employers of businesses with that exposure to use race as a proxy for increased susceptibility and to attempt to exclude members of that group from certain jobs, ostensibly based on a desire to protect that group from that exposure.

The potential for genetic stigmatization of socially identifiable groups is not confined to occupational settings. Conference participants expressed concern that a socially identifiable group can be stigmatized as being "prone" to a disease, as in the case of Ashkenazic Jews and breast cancer. Such stigmatization has even been institutionalized, as in the case of the severe social sanctions and mandatory screening requirements once placed on African Americans, inaccurately perceived as being at high risk for sickle cell anemia (Wailoo 2001).

Conference participants expressed concern that research into gene-environment

interactions in disease causation may inadvertently shift public perception of what causes disease from environmental factors to genetic factors, echoing historically racist pseudoscientific arguments about "bad genes." For diseases such as asthma that have both genetic and environmental components and that disproportionately affect people of color, there is concern that the social and policy climate surrounding genetic research findings will lead to the stigmatization and isolation of those groups as being "predisposed" to asthma, while drawing attention and resources away from the preventable environmental exposures associated with the disease. The reduction of risk factors in public policy and public health to individual or group characteristics is not just a legacy of the distant past. Symposium participants noted that communities of color often bear an unwarranted burden of perceived responsibility for health problems associated with environmental exposures, especially for those with unknown or complex etiology. Heart disease, cancer, and asthma, for example, are frequently attributed to poor lifestyle and diet, to the point of dismissing potentially valid associations between environmental exposures and those disease outcomes. For example, conference participants noted the frequent attribution of epidemic rates of inner-city asthma to indoor factors, such as the presence of cockroaches and environmental tobacco smoke (ETS) in the home. This emphasis on indoor pollutants, with comparatively less attention paid to outdoor air pollution, is cited despite the fact that asthma rates have increased sharply in the past 20 years without evidence of a concomitant increase in exposures to cockroach allergens and ETS.

As environmental studies scholar Giovanna DiChiro (Mt. Holyoke College, South Hadley, MA) noted during the conference, there are potential epistemologic and political challenges associated with environmental health genetic research. If variations in environmental response genes are identified as the focus of study, a different set of regulatory and response tools will emerge than when excessive exposures are identified as the source of the problem. DiChiro argued that identifying susceptible subpopulations as the focus of inquiry may lead to an impractical set of tools for remediating environmental health problems. She noted that for many EJ activists, the central question about the causation of disease is "What is the role of environmental toxins in causing disease?" These activists, although acknowledging the importance of understanding gene-environment interactions in disease causation, note that the point of intervention is to prevent disease. This emphasis is particularly true for communities with limited access to health care, who remain focused on environmental exposures rather than on individual biology.

Ethical issues in population-based genetic research: informed consent, group consent, and human subjects protection. Population-based genetics studies in environmental health raise a series of unique ethical concerns, particularly for communities of color. In particular, in genetic epidemiology studies that focus on entire communities or ethnic groups, the standard model of protection is inadequate. That is, the standard that individual research participants provide individual consent does not adequately protect groups against potential risks in such research. Models of community review and consent in genetic research have also been discussed elsewhere (Sharp and Foster 2000).

This issue of informed consent and human subject protection has been discussed and debated vigorously by many Native American communities. Harry shared her perspectives and findings regarding the impact of human genetic research on indigenous peoples, drawing lessons from the Human Genome Diversity Project (HGDP). The HGDP was discontinued in 1998, for a variety of reasons, including pressure from groups such as Harry's (Lone-Dog 1999). These and similar efforts have affected what genetic researchers are able to do when they collect samples from any community for research purposes. Harry noted that existing protections for human subjects pertain to the individual, not groups, and that real legal protection and policies to protect groups in research do not exist. She emphasized the lack of group consent that occurs if an individual is recruited into a study that highlights the individual's ethnic or sociocultural affiliation. Elsewhere, authors have critiqued the validity of using racial classifications of individual DNA samples in population-based research (Jackson 2000; Lee et al. 2001). Until protections are solidly in place, Harry suggested, communities should look at research models in which they define and control the research agenda. The rapid development of genetics advances has left open an unregulated domain of research protocols. However, recent efforts have been made to compose drafts of bioethical standards to address issues such as whom to consult if a certain group is affected by research (Indigenous People's Council on Biocolonialism 2000).

Patricia Marshall of Case Western Reserve University (Cleveland, OH) concurred with the need for researchers to seek out some form of community consent before embarking on research in which individuals are recruited based on their membership in particular ethnic groups or other communities. She further noted that study participants might not be aware of previous research studies and subsequently would not know the appropriate questions to ask. They might also be led to one understanding of the study's

goals that differs from the researchers' intended goals.

Discussion and Symposium Results

The following section summarizes the discussion among the participants at the Human Genetics and Environmental Justice symposium on 5 February 2002.

Perceptions of genetic research. The concerns and beliefs expressed at the EJ symposium spanned the spectrum from distrust to optimism. Many participants expressed the conviction that genetic research causes more harm than good for certain minority groups and should therefore be shunned in favor of better investment of community time and resources. Others voiced more optimistic beliefs that through careful oversight and participation in truly community-driven research, such studies could yield positive benefits for ethnic groups that have been historically excluded from or damaged by biomedical studies. A few participants noted potential benefits of toxicogenomics and the EGP such as the use of susceptibility data to limit pollution sources in overburdened communities. Other potential benefits for communities facing the highest exposures to chemical pollutants are a better knowledge of toxicity mechanisms and decreased uncertainties about low-dose and even synergistic effects of those pollutants.

Concerns. In addition to the concerns noted above about the dynamics between environmental health, genetic research, and communities of color, participants' major concerns related to genetic research focused on the rapid pace at which such research is unfolding with inadequate oversight by community advocates or other lay stakeholders. Others noted that although genetic research by government and private entities is often described as being conducted for the public interest, there are insufficient points of entry for public-interest or community-based organizations to participate in research oversight and agenda setting. Several participants expressed concern about the privatization of research, questioning the extent to which research taking place in the private realm will ultimately benefit poor communities. Many symposium participants expressed a concern that emerging genetic technologies may magnify existing inequalities in access to health care resources. Others noted that preventive and population-based approaches, such as exposure reduction, to environmentally influenced disease may one day be bypassed in favor of individualized "treatments" focused on gene expression—analogue to the "stepchild" fate that public health has experienced relative to the better-resourced field of biomedicine.

Recommendations. During the EJ symposium, an initial list of recommendations was

put forth to the regulatory and research community on ways to pursue a more effective community-driven research model and effectively address ethical concerns in genetic research. Participants strongly voiced the need for genetic research in the realm of environmental health to follow the model of community-based participatory research. This model is based on the principles that community residents are involved with all aspects of the research process, from setting the research agenda through data collection and interpretation; that research results are communicated back to the community in a timely and accessible manner; and that research is used to help improve the health of the community (Shepard et al. 2002).

The recommendations were the product of a mixed group of participants, including community activists, academics, professionals, and researchers. However, they do not represent any consensus from the EJ community. In fact, several participants clearly echoed the sentiment expressed by one participant, that "as a Native American observer . . . I cannot make recommendations to the NIEHS. Individual tribes and indigenous nations need to consult internally and make these decisions. It is a sovereign issue that only can be addressed by tribal leadership and their people" (Unpublished evaluation). With these caveats, other discussants put forth a preliminary list of important issues for research bodies to consider.

Communication and education. Community-based research goes beyond traditional models of informed consent to affirm that research designed to benefit the community is predicated on community knowledge of the biologic and social foundations of that research. In this case, it means that community residents who are asked to participate in research have a basic understanding of human genetics, gene-environment interactions, the EGP, and toxicogenomics, as well as a basic grasp of the social, legal, and regulatory implications of that research. This concept involves effective and adequate communication to the lay public and community residents about the scientific concepts underlying genetic research, as well as the goals of research projects. Communities must be informed about existing and emerging technologies in lay language and through appropriate and accessible mechanisms.

Many symposium participants acknowledged that some of the scientific concepts are difficult to communicate, particularly given that most communities are composed of a broad spectrum of individuals and families with diverse educational and language backgrounds. Nonetheless, they noted that it is not acceptable to substitute for full and informed community consent the rationalization that

"residents just don't understand the science." Framing education as a two-way process, participants sought a better appreciation by researchers of the realities of the communities in which they conduct research, including, for example, the actual environmental exposures faced by communities of color, the way community residents perceive and prioritize health risks, the potential for research outcomes to benefit or harm the community, the historical context of genetic research and research applications in communities of color, and the current realities of community- and workplace-level racism, classism, and other forms of discrimination.

Several symposium participants noted that researchers and others whom they termed "genetic optimists" often come across as arrogant, particularly toward those with differing worldviews or those who are distrustful of the unfolding genetic research agenda. Researchers who brush off community distrust of research related to genetics as "irrational" without considering the social and historical context that has given rise to this distrust widen the gap between themselves and those communities. Participants noted the importance for researchers, as both individuals and institutions, to explicitly identify the relationship between genetics and social issues, and to acknowledge and address the social and political contexts before this research begins. Others suggested that scientists could better understand their own biases through community orientations and mandatory training on community-based research.

Setting up appropriate communication mechanisms with the community, especially with study participants, was considered crucial for conducting ethical research that can benefit participants. Specific suggestions put forth during the symposium included the following:

- Plan and hold more town meetings and community workshops
- Make concepts clearer by using accessible language and visual aids, providing definitions, and explaining acronyms
- Be honest with communities about scientific uncertainties
- Build mechanisms for feedback to communities by community representatives
- Return the results of research to the community, using appropriate language
- Use a variety of communication tools, including web sites, newsletters, journals, and community newsletters
- Use multiple languages as appropriate.

Although providing timely feedback on the study results was identified as critically important, it was also acknowledged as a difficult problem because the community may want immediate feedback. Preliminary results should also be made available to study participants on a case-by-case basis.

Finally, symposium participants recommended better communication between regulators, researchers, and the public using mass media or other popular communications avenues. They noted the especially pressing need to ensure that the media and policy makers are well versed in the complexities of genetic research.

Community oversight and agenda setting. Symposium participants noted the key distinction between communities of color playing a central role in setting the research agenda versus being asked to play an advisory role once that agenda has been set. DiChiro remarked in the symposium that the perception that the genetic revolution “ship” has already left the harbor does not contribute to effective partnership building, leaving communities feeling unable to intervene meaningfully in the process. It is important for communities of color to have a significant role in overseeing the goals and process of research projects whose results can have far-reaching impacts. One suggestion was made to encourage or mandate significant community representation on institutional review boards (IRBs). For meaningful participation, community representatives ideally will go through training to prepare them for serving on an IRB.

Participants expressed a desire for researchers to develop a precautionary, systemic, and holistic approach to questions of genetics and environmental health. Several suggested that genetics and gene–environment research would benefit from a multidisciplinary research approach that encompasses sociology, anthropology, human rights, and public policy. Another specific suggestion for the NIEHS to better address community concerns is the creation of a community advisory board of community members on all NIEHS review committees regarding requests for proposals.

Meaningful consent and participation. Full and informed community participation in the process of genetic research, particularly for population-based research, and especially where communities have not played an active role in setting the research agenda, will be key for its ethical application. One suggestion for ensuring more informed participation is to ensure that participants truly understand the “consent form.” In addition to basic steps such as putting the form in basic language, ensuring both oral and written consent, and making it a uniform document, symposium participants suggested giving community workshops on the information contained in these forms, particularly around such issues as the use and disposition of samples.

Participants also noted the importance of ensuring that community representatives truly reflect the community. Most communities are not homogeneous, nor can they be fully represented by one or two voices. Representation

from a wide spectrum of groups is often desirable, especially in diverse communities. Researchers are urged to define and examine who is authorized to speak for the community and whose voices are heard and not heard when the community representatives speak.

Building partnerships. Kim J. Nickerson of the American Psychological Association (Washington, DC) suggested that strategies to strengthen the relationship between researchers and communities of color are crucial for developing true partnerships for community-based genetic research. Currently, communication barriers exist because communities of color and researchers differ both in the language they use and in their respective agendas. Nickerson and symposium participants put forth the following specific recommendations for developing mutually beneficial partnerships:

- Allow time to build partnerships with communities
- Strive to build true partnerships based on shared power, resources, and benefits
- Think in terms of long-term relationships
- Have the researcher(s) join the community in some meaningful way
- Advocate for the hiring of community members in key staff and consultant positions
- Share knowledge of reports, articles, chapters, and such, that result from the research
- Disseminate the information to the community and transform it into positive action
- Advocate for training and education for the community, both specialized and general.

Several participants noted that community groups are already overburdened with responsibilities, and often partnerships with academic institutions do not come with adequate compensation for the community group or community residents, or that community contributions to the project are undervalued compared with academic contributions. Some felt that “partnership building” is a clichéd phrase that has lost its substantive meaning—particularly the emphasis placed on equality. Others pointed to historically rooted power imbalances between the biomedical research community and communities of color as one of the reasons for the distrust of genetic research and researchers. Participants also urged the NIEHS as well as other research funders to foster partnerships between genetic researchers and community/EJ activists and to ensure that researchers consider EJ issues. One way to do so is to include a publication requirement that any ethical issues raised by research be explicitly addressed in research reports.

Participants also encouraged research agencies to invest more resources in community-driven research, voicing the conviction that this model of research is the most likely to return benefits to communities of color that translate into improved health outcomes.

These agencies can also encourage genetic researchers and EJ advocates to attend conferences together and to become joint principal investigators on projects. Participants pointed to the need for long-term capacity building and leadership development of community groups and residents as researchers, not just as research participants or subordinate partners. Provision of training on genetics and on research ethics, as well as support of minority researchers, was cited as possible leadership development activities.

Conclusion

As with many applications of genetic research, environmental health genetics and research into gene–environment interactions is a complex, rapidly evolving combination of opportunities and challenges, particularly for communities of color. As this research and its social and policy implications unfold, ongoing dialogue, shared approaches, and a community-driven agenda will be essential for maximizing promised benefits. The Human Genetics, Environment, and Communities of Color conference and subsequent Human Genetics and Environmental Justice symposium were a first step in beginning this transparent, collaborative approach to this research.

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