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Crossing the Chasm of Mistrust: Collaborating With Immigrant Populations Through Community Organizations and Academic Partners

As a community partner and an academic researcher, we experienced the direct and extended benefits of a relatively small-scale, community-engaged informed consent process that developed in an immigrant occupational health study, *Assessing and Controlling Occupational Health Risks for Immigrant Populations in Somerville, Massachusetts*.

The practice of human participants research played a positive role in the community, and both community partners and researchers, as well as the larger academic community, reaped unexpected benefits during the five-year project (2005–2010), which continue into the present.

Lessons learned from our experience may be helpful for wider application. (*Am J Public Health*. 2013;103:2126–2130. doi:10.2105/AJPH.2013.301517)

Alex Pirie, BA, and David M. Gute, PhD, MPH

AT A TIME WHEN EXTRAORDINARY health disparities in the United States are coupled with an increasing reluctance on the part of vulnerable populations to support or participate in health research, it is crucial to engage with these communities to ensure the integrity of human participants research. Gaps in trust between vulnerable communities and researchers have emerged for a variety of reasons, including historical injury at the community level and the current media coverage of the lack of oversight on medical devices (e.g., metal-on-metal hip replacement problems¹) and clinical trials.² The integrity of protection should be enhanced,³ and at-risk populations need education in the protections that exist and the benefits of engaging in health studies through such established research mechanisms as

clinical trials research or newer modalities such as community-based participatory research.⁴

Community-based participatory research often requires active negotiation of the social and cultural differences that separate community organizations from academic partners. We gained insights into this process from our research experience with immigrant populations living and working in Somerville, Massachusetts.

THE SOMERVILLE PROJECT

Assessing and Controlling Occupational Health Risks for Immigrants in Somerville, Massachusetts, funded by the National Institute for Occupational Safety and Health (NIOSH), involved a community organization, the Immigrant Service Providers

Group/Health (ISPG/H); a provider of health care, Cambridge Health Alliance; and an academic partner, Tufts University. Other community partners were the Haitian Coalition, the Community Action Agency of Somerville, the Brazilian Women’s Group, and the Massachusetts Coalition for Occupational Safety and Health. All of these organizations worked collaboratively throughout the project period. The objectives of the project were to enhance the capacity of the community partners to address occupational health issues for the populations they serve as well as to gather quantitative and qualitative information regarding immigrant occupational health.⁵ This work began in 2005 and ended in 2010.

An initial step in the multifaceted project was to gather

information on self-identified immigrant workers living or employed in the city. Somerville is a gateway city—an immigrant entry point—and approximately 30% of the population is not native born. It is a heterogeneous population, with 52 languages spoken, but three communities predominate: Haitian, El Salvadoran, and Brazilian. Because these three groups represent the majority of the city's immigrants, the research team decided to focus on them.

Our community partners had an eight-year history of successful work with bilingual adolescent students in the Haitian and El Salvadoran communities. These youths were identified as teen educators in previous, federally funded outreach programs that addressed tobacco education and brownfield documentation and education. In addition to their ability to broadly communicate with their communities, they were the primary conduits of information into their immediate, extended, and often non-English-speaking families. Because of this experience and the presence of the immigrant community adult youth leaders, we directed a substantial portion of our activities toward the recruitment and training of two similar groups of youths, Haitian Creole and Spanish speaking, to develop and, under adult supervision, administer an immigrant worker survey. Because another segment of the grant focused on the development of a Brazilian women's green housecleaning cooperative,⁶ we decided to use a Portuguese-speaking graduate student and an adult member of the Brazilian community partner to administer these surveys in Portuguese when required.

BUILDING COLLABORATIVE RELATIONSHIPS

The first months of the grant process involving the youths were devoted to the development of the survey instrument. Initially, adult immigrant leaders, Tufts faculty, and A. P. (the ISPG/H coordinator) worked with the youths to review an informal survey from earlier community health fairs. Brainstorming sessions on immigrant occupational categories and work hazards, discussions of other kinds of studies, and sessions with academic partners and adults who were knowledgeable about the community followed. The administrative director of the Tufts social, behavioral, and educational research institutional review board (IRB), Tufts faculty, and staff from the Massachusetts Coalition for Occupational Safety and Health and the Occupational Health Surveillance Program of the Massachusetts Department of Public Health shared their expertise during survey development.

The final draft was sent off into what, to the community partners and the youths, was the lengthy and somewhat abstract IRB approval process. The initial approval took several weeks. Although they were engaged in other skill-building activities (a Tufts faculty member conducted a public speaking workshop, and the Massachusetts Coalition for Occupational Safety and Health conducted a interactive training session on workplace hazard mapping), the youths were first and foremost adolescents: action oriented and eager to begin the survey work. When the survey came back with IRB approval, they began practice sessions and immediately noticed an unfortunate mistake. Two of the questions had

been transposed and created confusion in the survey's flow. We had no option but to send it back, corrected, for reapproval. Even though this would be expedited and quicker, the young people vociferously objected: "Again?! Why can't we just fix it and do it?"

A Teachable Moment

At this point D. M. G. (the principal investigator of the NIOSH grant) recognized the opportunity to combine a teachable moment with the need to pause the process. He proposed, and the community leaders agreed, that the youths be brought onto the Tufts campus for a showing of a movie dramatizing the Tuskegee untreated syphilis story, *Miss Evers' Boys*.⁷ He felt that the reasoning behind the IRB requirements should be communicated to the young people and to the community partners representing Somerville's vulnerable immigrant communities. The showing of the film led to two very intense discussions in which the youths and the adult community and academic partners fully engaged in the issues raised.

Simultaneously, in practice sessions with the youths, it became clear that our informed consent form was too complicated and written at too high a literacy level for the expected participants. We knew we were likely to encounter undocumented and, in some cases, native language-illiterate participants, a fact that was reinforced in discussion with the community partners and the teen educators, and we had obtained oral consent from the Tufts IRB with the stipulation that the survey takers be supervised by their bilingual adult leaders.

As we worked on simplifying the form, D. M. G. suggested building on the impetus toward a fuller understanding of the role and purpose of human protection

by training the adult community partners to become certified as individual investigators. All agreed, and after a few small seminar-like discussions, the Haitian and El Salvadoran leaders and A. P. read the required material, observed D. M. G.'s own recertification, and then took the Collaborative Institutional Training Initiative (CITI) online exam at their homes or workplaces. All achieved certification, and a member of the Brazilian community partner group was subsequently certified as well.

The adult team, with the support of D. M. G. and a doctoral student working on the project, then completed the training of the teen educators—who now had a much clearer understanding of the role and purpose of human protection—to simplify the consent form, which received expedited approval, much to the satisfaction of the youths. From the standpoint of the grant objectives, a significant basic task had been completed and the work could proceed. For the community partners, something equally important had occurred, and a much broader set of projects flowed from the CITI experience.

Ordinarily, the concept of the teachable moment is part of the educator's domain, a moment when a teacher recognizes an opportunity where the student is open to and interested in learning. For us, the moment began that way, but over time an unexpected reciprocity developed: we had as much to learn from the initial viewing of *Miss Evers' Boys* and the ensuing discussion as did our young community partners. We learned some lessons immediately, and over time we gained several realizations that had much broader application and utility outside of and beyond our

grant process. These outcomes fell into two broad categories: activities that increased community skills and built relationships that supported collaborative research and activities that increased the capacity of community human studies protection mechanisms.

An Interdisciplinary Opportunity

During the discussion with the immigrant youths about *Miss Evers' Boys*, the youths raised an important question: "How could they do this to their own people?" This provoked an intense discussion about slavery; the Civil War; the Civil Rights Movement; self-esteem; the Haitian Revolution, which culminated in independence in 1804; and racial pride. It became apparent to the adults present that these youths, who arrived in the United States most often during their middle school years, had very little knowledge of US history, and, in most cases because of deficiencies in the educational systems in their home countries at the time of immigration, they had a similar lack of knowledge about their own history.

A. P. discussed this finding separately with immigrant leaders and other ISPG/H partners and began looking for potential academic partners who might be willing to explore these educational gaps. A Tufts faculty member from the Eliot-Pearson Department of Child Development Education had been working in this area and agreed to participate. This quickly led to an academic partnership with another ISPG/H member group, the Welcome Project, to look at the educational and personal benefits to the immigrant youth participants in their Liaison Interpreters of

Somerville project, a relationship that was initially funded by a seed grant from the Tufts Community Research Center.

Community Human Studies Protection

During the last year of the NIOSH grant, a Somerville neighborhood with a significant immigrant population and an early childhood educational center were discovered to be above a toxic groundwater plume containing perchloroethylene and emanating from a newly identified tier 1C brownfield site. The ISPG/H was asked to support the development of a neighborhood group and obtained funding to hire a licensed site professional to represent the community.

At the same time, a Tufts MD-MPH program faculty member offered to use a seminar class to conduct a health survey of perchloroethylene exposure symptoms. Because the medical students conducting the survey were likely to encounter non-English speakers in the randomized study (the afflicted neighborhood and a demographically similar nearby neighborhood), the IRB required that there be human studies-certified interpretation available. Neither the Tufts class nor the ISPG/H had the financial resources to support this, but, because of the previous CITI certifications, qualified interpreters were already in place. Through the NIOSH grant process the community had acquired the capacity to support a health study.

Community Education About Medical Research

In 2008, A. P. agreed to participate as a community representative in the community engagement component of the Tufts Clinical Translational Science Institute

(CTSI), Aligning Research for Community Health, and the Community Engagement Research Advisory Board at the Harvard Catalyst. At Tufts, the possibility of supplemental funding arose. The ISPG/H had been considering an educational project in Somerville for local community organizations to disseminate some of what had been learned in the NIOSH work and our human studies protection experience.

In response to a funding discussion within Aligning Research for Community Health, A. P. proposed a scaled-up version. The general idea was accepted and a more extensive project was developed and funded through a supplement to the CTSI award. Over two years, 20 community organizations with an interest in medical research sent staff to participate in Building Your Capacity, which offered six-month-long seminars to two cohorts.⁸ The *Miss Evers' Boys* curriculum from the NIOSH grant was also incorporated into this course, which was developed to train community partners in how to better work with medical researchers. D. M. G. and A. P. participated in one of the sessions, and A. P. served on the planning and curriculum committees. The program aimed to develop community capacity and to improve relationships, build trust, and support one of the goals of the CTSI mechanism by increasing awareness of and familiarity with clinical trial research.

D. M. G. and A. P. came back together to work as co-investigators on a subsequent immigrant-focused project, Live Well: Assessing and Preventing Obesity in New Immigrants, supported by the National Institute of Child Health and Human Development. Their earlier work together and subsequent informal collaborations and discussions greatly

facilitated the initial relationship-building stages of this large and complex obesity study, a mix of clinical trial research (nearly 400 mother-child pairs in three target languages) and community-based participatory research. The community partners, now better educated in human studies protection and more empowered, asked for and obtained an agreement to build into the process the option for participants in the control group to be offered a modified version of the intervention. In addition, the intervention itself was based on a novel popular education model suggested by the community partners, and we agreed to give the community a strong role in dissemination.

SUPPORTING HUMAN STUDIES PROTECTION

In an early meeting of its community engagement component's advisory board, the Harvard Catalyst staff solicited community input about the tasks that should be prioritized for the group. A. P., on behalf of the membership of the ISPG/H, with other community groups concurring, discussed the lack of trust in medical research in general and the reluctance to participate in clinical trials and related the *Miss Evers' Boys* experience. Representatives of the community mentioned the need for community education about personal protection and the consideration of community-wide protection, particularly with the growing influence of epigenetic studies. The director of regulatory affairs operations at the Harvard Catalyst joined the next meeting to continue this discussion. Over the course of several meetings, the group formed a subcommittee, a partnership of

community representatives who were members of the Harvard Catalyst Community Health Innovation and Research Program's Community Advisory Board and the Regulatory Knowledge and Support Program.

This subcommittee provided a panel presentation on community-engaged research for the June 21, 2011, Office for Human Research Protections Boston conference, sponsored by the Dana–Farber Cancer Institute, Protecting Human Subjects in Research: Blending Regulatory Requirements and Best Practices. A. P. was a panelist and served on the panel planning committee. In addition, the subcommittee is developing a community-focused report with the goal of extending community-wide education about protection.

Both the Tufts and the Harvard CTSI organizations collaborated on a joint presentation to legislators and interested members of the general public, a Clinical Research Education Day and Health Fair on October 21, 2011, at the State House in Boston. Massachusetts State Representative Jeffrey Sanchez, chair of the Joint Committee on Public Health, hosted and sponsored the event. A. P. led a panel discussion on community-engaged research and participated in the event planning, the director of the Tufts community engagement component presented the research work accomplished by participants in the Building Your Capacity course, and the Harvard Catalyst regulatory director led a discussion of community participation on IRBs. The audience for the event included Massachusetts state legislators, Tufts and Harvard staff and faculty, and members of local health-focused community organizations.

LESSONS LEARNED

Often, in academic–community partnerships, the work at hand, the scheduling requirements imposed by the grant mechanism, and the subsequent emphasis on publication create a work process whose complexity and urgency can easily lead partners on both sides of a community-based research project to overlook the opportunities and expandable moments that can occur in collaborative work. In our case, the external delay that the IRB process created provided a pause that we were able to turn to the advantage of academic and community partners and the teen educators engaged in our work. The delay also led to opportunities to deepen mutual relationships of trust, expand community capacity through education in human participants protection, and support the CITI certification of community partners. Although this delay was not planned, the benefits of early engagement on matters of confidentiality and human participants research were clearly evident. At the same time, our work allowed us to feed insights and lessons learned from the community partners back into the academic and regulatory world to the benefit of the involved stakeholders.

We also learned more subjective lessons: trust is best developed over time and through shared experience, being receptive to community input can lead to positive outcomes and influence that transcend the scope of the original project, and unanticipated events often offer the greatest opportunity for true learning and understanding.

Beyond the specific outcomes, our work had personal educational implications. The original

intense discussion with Hispanic and Haitian youths about slavery, race, and the consequences of racism gave us a much deeper understanding of the personal and institutional obstacles faced by both immigrants and members of other vulnerable communities in accessing health care and the reluctance of members of these communities in general to engage with medical researchers. It was one thing for us to watch *Miss Evers' Boys* as White adults, but a quite different experience to see it through the eyes of young people of color. What we learned and what we were motivated to develop outside of the original funded work underscored the importance of engaging with and fully listening to our community partners. This is a lesson we will carry into future collaborative work.

The protection of immigrant populations in human participants research touches on many facets of the prevention and treatment continuum. It encompasses the successful completion of treatment regimens,⁹ differential patterns of utilization of mental health services,¹⁰ and impacts of citizenship on Medicaid and health insurance coverage.¹¹ These points of departure from normative protection for immigrants are played out against a well-established backdrop of race and class as well.¹² Such constructs only make more difficult the development of higher levels of trust between investigators and immigrant populations. What is unquestioned is the influence—often subtle and sometimes definitive—that immigrant status can have on the health status of populations.^{13,14} What we have gained from our small-scale journey over this landscape is that trust is best built upon shared experience, the enhancement of capacity, and an

appetite for this work in both community and academic partners. ■

About the Authors

Alex Pirie is with the Immigrant Service Providers Group/Health, Somerville, MA. David M. Gute is with the Department of Civil and Environmental Engineering, Tufts University School of Engineering, Medford, MA.

Correspondence should be sent to Dr David M. Gute, Department of Civil and Environmental Engineering, Tufts University School of Engineering, 200 College Ave, Medford, MA 02155 (e-mail: david.gute@tufts.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

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Contributors

A. Pirie conceptualized the subject of the article and wrote the first draft. D.M. Gute contributed to the conceptualization of the article and made substantive additions to it. Both authors contributed to the final version of the article.

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