



Transferring Knowledge About Human Subjects Protections and the Role of Institutional Review Boards in a Community-Based Participatory Research Project

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Among the first tasks in a collaboration between Tufts University and community organizations in Somerville, MA, was designing an interview instrument to assess occupational health needs among immigrant workers. Human subjects protections was a critical issue, but community partners were not well informed about the need for such protections or the role of the institutional review board (IRB).

During research meetings, members of the team from Tufts trained community collaborators to work with research participants and organized a presentation by a key university IRB administrator.

We present findings from the process evaluation of this project and suggest ways to (1) assess community partners' understanding about working with research volunteers, (2) train collaborators, and (3) involve IRBs. (*Am J Public Health*. 2009;99:S526–S531. doi: 10.2105/AJPH.2008.155390)

THE IMPORTANCE OF THE

community-based participatory research (CBPR) model has been well demonstrated, as have the benefits for both researchers and community partners. In addition

to their many skills and talents in creating, maintaining, and evaluating community programs, community partners may enable researchers to gain access to communities where there are known or perceived barriers to the recruitment of participants. Collaboration in research with academic partners may provide community organizations and leaders access to university resources, increase their own presence and position within their community, and add to their legitimacy with community members.^{1,2} Working together, both partners become involved in identifying social problems, understanding the importance of such problems to community members, and generating interventions and new research hypotheses. Examples of successful CBPR approaches include the study of the health of young children, behaviors of drug users and dealers, and attitudes of members of close-knit religious communities.^{3–8}

One question often addressed in CBPR is how to conduct ethical and participatory research in a community where there are strong community organizations with leaders who do not have extensive research training. In such cases, academic researchers may undervalue the role of the community partners,

and community members without advanced formal education may be taken for granted and have their opinions dismissed, particularly when research findings are interpreted and disseminated. University researchers may feel that they have worked hard to establish their own credibility in an area of expertise and find it difficult to accept the expertise that community leaders have gained through experience.

These attitudes can make partnerships uneasy and can lead to difficulties when planning future research endeavors.^{9–11} The participatory component of CBPR may then be reduced to the use of the community leaders to gain access to participants or to periodic meetings of a community advisory committee to hear a progress report from the research team. Academic researchers and community partners need each other to address complex social and health issues, even though trust can be difficult to establish and maintain. An important dimension in this relationship is the degree of authority over the research plan, program execution, and interpretation of results exercised by the community.^{12–14}

For their part, community leaders are sometimes apprehensive that university researchers

will simply use their community as a research laboratory and then abruptly disappear when the study is completed. Community-based organizations are often concerned about control of research findings that may cast a negative light on their community when findings are published and may be covered in the popular press. Examples include studies that have focused on gang crime, prostitution, and environmental waste.¹⁵

In addition, community organizations that work directly with community members who become human research participants often do not have access to an institutional review board (IRB). Because their mission is programming rather than research, an IRB is not required and oversight may be accomplished by an advisory board or board of directors. By contrast, university research protocols are reviewed and approved by an IRB whose charge is to monitor human subjects protections and risks to human participants in university research. When university IRBs are charged to review and approve protocols for which community organizations are full partners in the research, misunderstandings can arise and can lead to mistrust and eventually to the demise of the partnership.



During a CBPR project between Tufts University and organizations in Somerville, MA, we discovered gaps in knowledge and accumulated mistrust. We sought to determine whether an education and training intervention involving both our community partners and IRB leadership could resolve these issues.

METHODS

The context of our intervention was a CBPR project aimed at identifying and controlling occupational health and safety risks among immigrant workers in Somerville, MA. Somerville is often characterized as a gateway community for new immigrants to the United States. It is a mid-sized city with approximately 80,000 residents and has considerable cultural and ethnic diversity in a relatively compact 4-square-mile area. We sought to establish true participation at the community level by involving community leaders, organizations, and a group of teen educators^{16–22} in gaining access to immigrant workers, designing a survey of immigrant workers, reviewing the process of data collection, and participating in data analysis. We discovered that these goals brought with them challenges and opportunities in transferring research capability to the Somerville community leaders and teen educators that were not contemplated in our original study design.

Tufts is a research-intensive university with 3 campuses in the United States. The Tufts social, behavioral, and educational IRB was responsible for approving the research protocols for Assessing

and Controlling Occupational Health Risks to Immigrants in Somerville, MA, a 4-year study funded by the National Institute for Occupational Health and Safety. This board reviews research conducted at the schools of arts and sciences and engineering and the Fletcher School of Diplomacy. In line with federal mandates, the IRB has 14 members, drawn from the university faculty and staff and representatives of the community.

Members of the Collaboration

Our study's program announcement called for 3 principal participating organizations. Tufts University was the academic partner, the Immigrant Service Providers Group/Health was the community organization, and the Cambridge Health Alliance was the health care provider.

Despite substantial collective experience with partnerships in the city of Somerville, the academic researchers could not have established credible access to the community without partnering with viable and well-known local organizations. Along with the many skills and talents of their leaders and members, these community organizations provided not only access to the study population but also the ability to transcend barriers between the federally funded project and the immigrants, some of whom may have been working and living in the United States without documentation.

In addition to the 3 principal members of the collaboration, several Somerville-based organizations became involved in the

study: the Community Action Agency of Somerville, the Jovenes Latino program, the Haitian Coalition, and the Brazilian Women's Group, all of which had strong connections to important local constituencies. In addition, technical expertise on design and implementation of occupational health and safety interventions was provided by the Massachusetts Coalition for Occupational Safety and Health. All of these groups were involved in survey design and data collection.

The community leaders had previous, though not extensive, research experience. For example, the coordinator of the Immigrant Service Providers Group/Health had a bachelor's degree, extensive science curriculum development experience, and previous CBPR experience working with Tufts University (notably the Shape-Up Somerville childhood obesity intervention²³) and was a member of the steering committee of the Tufts Community Research Center. The leaders from Cambridge Health Alliance and Massachusetts Coalition for Occupational Safety and Health had formal advanced education, including a medical degree and a master's degree, and relatively extensive research experience.

One goal for the project was to create a participatory environment within the CBPR model.^{24–27} During the project design phase, we built in tasks to involve community leaders in the preparation and implementation of surveys, discussion of the analysis plans, and interpretation of results.

These tasks were designed to help the academic researchers

transfer research capability to community-based organizations. The goal was to give community leaders, particularly in our partner organizations, additional experience and training in survey development, implementation, and analysis, with assistance provided by coinvestigators at Tufts University. In early meetings with community partners after the study was funded, we began to outline the strategy for preparing and implementing the survey of immigrant workers in Somerville. We sought to include the community leaders and to respect the participant base they represented. We quickly introduced the concept of the Tufts IRB and informed consent.

Teen Educators

Because of the difficulty of identifying, establishing dialogue with, and developing trust with immigrant populations, as well as the nature of the population we were trying to reach, which included both documented and undocumented workers and employers, we proposed to use bilingual youths as teen educators, acting under the supervision of experienced adult youth leaders, to reach out to immigrant workers in Somerville. Our grant proposal noted the language and cultural differences within the study populations and the role adolescents have traditionally played both in peer education and in immigrant communities, as an interface between older immigrants and native citizens.¹⁹ Two of our partners, the Community Action Agency of Somerville and the Haitian Coalition, often



employed adolescents to help establish and maintain community networks. We believed that the youths would be able to overcome the obstacles in approaching and connecting with our target population and that experience with an academic research project would be of substantial benefit to the adolescent collaborators.

The resulting occupational survey was largely developed by the teen educators, who received training from Boston-area occupational safety and health experts and Tufts faculty associated with our grant. Questions about immigration status were not included in this survey or in any of the other data-gathering activities pursued under this grant, a decision affirmed by all of the project partners (academic, clinical, and community). Teen educators solicited respondents' oral consent under the supervision of IRB-certified adult leaders (in a few instances Tufts University students administered the surveys).

The survey involved a short (average time 10 minutes) dialogue between an teen educator and a respondent. The survey's 23 questions were grouped into 3 sections: background (for example, country of origin, age category, gender), occupation ("What kind of work do you do at your primary job?" "If you have a profession that you cannot currently practice, what is it?"), and health and safety ("Did you receive training that was specifically about health and safety?"). The survey was later modified to include additional health questions for use at an immigrant

occupational health fair in November 2008.

RESULTS

Some potential risks to human participants were identified from the start by the Tufts research team:

- Worker participation might become known to employers, who could retaliate by terminating employment, restricting promotion, or reducing salary increases.
- Employees might reveal that they did not hold a required Massachusetts license to perform residential or business-related services, thus putting both themselves and their employer at risk for possible legal action.
- Employees and employers might not be in compliance with Massachusetts tax laws and withholding requirements or participate in mandatory Massachusetts worker compensation insurance, also putting them at risk for legal or criminal action.
- Employers might not carry required liability insurance or provide required health and safety training and equipment.
- Some workers, and possibly employers, might be undocumented immigrants, who could have their status identified via the project and be arrested and possibly deported.

We further identified risks to the participating teen educators who would be conducting the surveys with immigrant workers. The primary risk was being

identified in their communities as acting on behalf of authorities and in opposition to the interests of community employers and workers. Also some risks could possibly extend to the families of the teen educator and related adult workers. Finally, we identified risks to participating community organizations, such as the risk of being perceived as acting in consort with federal and state agencies in opposition to community and immigrant interests.

As we began the process of designing the first survey document and implementation plan, some unanticipated questions came from the community partners. We expected that they would be somewhat protective of their community members and might raise objections to methods that appeared too intrusive. However, we found that often community leaders questioned the level of caution we proposed to exercise in the data collection process as well as the importance and relevance of policies and procedures designed to protect confidentiality and human participants in general. For example, the discussions about how to obtain informed consent for the survey of immigrant workers inspired these and similar inquiries:

- "Why does Tufts require all of this bureaucracy? We survey our communities all the time and no one worries about this."
- "If they answer the questions then they are giving their consent; if they don't want to answer, they won't."
- "I can identify the people in my organization who will want to do

this survey; the consent form will just scare them away."

- "We will hold a health fair and then just ask for the information."
- "Why do we need Tufts to approve what we are doing in our own community?"

As a result of these conversations, the Tufts research team identified 3 ways to address gaps in human participant policy experience in the community: (1) education—we provided a working knowledge of the role and operation of an IRB for all community-based partners, both those with and those without ongoing research activities, that included a brief history of the development of human participant protections and motivation for IRB existence; (2) training—we provided training on research design, informed consent, and survey administration, with a discussion of potential abuses and costs to study participants; (3) dialogue—we addressed questions, within both the community and the university, about each other's capabilities and motives and sought to increase the level of trust between community advocates and university staff.

Education and Training

We related anecdotes from the past that graphically illustrated the need for IRBs, such as the Tuskegee syphilis experiment, the crimes committed by Nazi doctors in the name of research, and the more recent Johns Hopkins lead paint experiment.^{28–31} We also gave examples from our own research experience in which the IRB



process had helped us identify risks unforeseen by researchers and develop protections for participants. We extended this training beyond the key leaders of our community partner groups to include the teen educators who would be going into the community to implement the surveys.

We met with the teen educators and talked about our own research projects and what we had learned firsthand about confidentiality and protection of human participants. These discussions brought the subject to life and made the instruction a shared dialogue that involved the adolescents in our own learning process. We also used role playing to demonstrate how informed consent is obtained and to identify possible problems and misunderstandings. This effort was invaluable because it not only educated the adolescent but also helped us identify words in our consent script that had not translated well, words that our adolescent collaborators did not fully understand, and places in the script that made them feel awkward or uncomfortable. We were able to make small changes that qualified for expedited IRB review and have our consent form ready for the first data collection event.

Dialogue

We opened a dialogue with the community partners and the teen educators, who helped us identify additional risks to participants. For example, both the partners and the adolescents pointed out that the adolescents might also find their part-time jobs at risk if

their employers learned of their participation in the project. Further, they pointed out that adolescents could lose friendships or even risk being bullied by peers who perceived them as acting in consort with unfriendly authorities, particularly if peers' families believed that the wage earner or the family had been harmed by the project.

We decided to bring the Tufts University IRB administrator to a face-to-face meeting with our community partners. This meeting was a success. Key outcomes were the demystification of the Tufts IRB process and recognition of our shared intent to prevent harm to the immigrant community in Somerville. Our commonality of purpose became a dominant theme for both researchers and community leaders.

The recognition that academics and community collaborators had much to learn from each other about the safe implementation of this project strengthened the sense of partnership in both groups. Importantly, 5 of the community leaders who were partners in this research completed the Tufts University IRB training requirements to qualify as individual investigators for projects and proposals at Tufts University.

During the course of this project, our research team, which included the leader of the Immigrant Service Providers Group/Health as a coinvestigator, submitted a new RO1 proposal to the National Institutes of Health, which was funded in November 2008. We believe that the inclusion of a community member as

a coinvestigator was key to the success of this grant proposal.

DISCUSSION

Academy-based CBPR researchers must recognize the need for a transfer of experience and formal training on IRB issues to community members when planning a CBPR project and must include time, expertise, and cost for this in the research proposal. It cannot be overstated how effectively this endeavor can raise the level of community expertise in research, facilitate and deepen the research process, connect the community to the researchers and the university, and, most importantly, provide a community capability that will long outlast the project. This empowerment of community leaders opens the door to further collaborations with the host university as well as with other research centers.

Academic researchers cannot assume that community partners are highly knowledgeable about human subjects protections and risks to participants, or about the particular requirements for the creation of valid data, even when the partners have frontline interaction with the community. The examples of research in the past that failed to protect the rights and safety of human research participants illustrate the complex nature of these protections and their interpretation. Because community organizations do not conduct large-scale research on their own and because the surveys and questionnaires they sometimes field are aimed at their own membership and not at publication, there is no reason to

expect they have had IRB training. When university researchers are involved and peer-reviewed publication is a desired outcome in addition to popular media coverage, issues of human participant protections and the quality of data become much more salient.

An important community benefit to bringing in the IRB is the extension of this knowledge and expertise to the activities of community organizations. This extension has already affected the grant-writing activities of our community-based partners. Although small community organizations have long written grants, they are increasingly in need of outside funding and are learning that their proposals must include adequate consideration of human participant protection. IRB training and certification represent a concrete example of the transfer of research capability from the academy to the community as a direct result of CBPR. Successful participation in IRB-certified activities with university and medical partners adds considerable depth and validity to a broad spectrum of grant applications made by community partners.

Recommendations for University Researchers

It is critical for academic researchers to involve their community partners with the IRB as early in the research process as possible. Mistrust of science and research is widespread in the general population,^{32–34} but meeting with an IRB administrator or representative can lessen the mystique of IRB oversight for the



community partners, elucidate the goals and process of the IRB, and help to establish trust on both sides. Face-to-face open discussion of intentions and goals shows all parties that they share the aim of both protecting community members and giving them voice. We found that a remarkable amount of social capital for the university and for the community partners was created in the face-to-face meeting and subsequent interaction.

We also recommend that researchers provide examples from their own research experience to reinforce the traditional human participant protection examples found in the literature. Researchers who explain how their own survey had unintended effects and what it took to take corrective action may present a more motivating example to community partners, particularly when these examples are combined with a discussion of the historical events that contributed to contemporary IRB rules.

Finally, we learned to communicate about IRB issues as often and as clearly as possible, with both our community partners and our own IRB, to minimize last-minute surprises. When a study involves human participants and is carried out by collaborators with a wide range of backgrounds, all verbal communications should be followed up with a written memo to both community partners and the IRB. Once everyone understands the importance of communication when making changes and revising documents, the mechanics are relatively straightforward. ■

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Contributors

R.R. Hyatt helped design and deliver the informal IRB training sessions with the community partners, presented an oral report on this topic at the 2006 American Public Health Association annual meeting in Boston, and led the writing of the paper. D.M. Gute supervised the IRB training with the community partners and coordinated with the community partners. A. Pirie led the group of community partners and shared in the IRB training. H. Page served as the principal IRB administrator at Tufts University at the time of this project and met with the community partners. I. Vasquez and F. Dalembert, leaders of 2 of the significant community partners in this project, participated in the IRB training and reviewed the article.

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Human Participant Protection

All research activities for this project were reviewed by the Tufts University institutional review board.

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The Role for Community-Based Participatory Research in Formulating Policy Initiatives: Promoting Safety and Health for In-Home Care Workers and Their Consumers

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Although community-based participatory research (CBPR) can be effective in influencing policy, the process of formulating policy initiatives through CBPR is understudied. We describe a case study to illustrate how alliances among various community partners could be united to formulate policy directions.

In collaboration with partners, the National Institute for Occupational Safety and Health initiated a project aimed at improving health and safety for low-income elderly and disabled persons and their in-home care workers. Community partners and stakeholders participated in focus groups, stakeholder interviews, and meetings; they played multiple roles including identifying organizational policy changes the partners could initiate immedi-

ately, as well as broader public policy goals.

Results indicated that a strong community partnership, participation, and shared values contributed to successful formulation of policy initiatives. (*Am J Public Health.* 2009;99:S531–S538. doi:10.2105/AJPH.2008.152405)

COMMUNITY-BASED PARTICIPATORY research (CBPR) has gained support as an effective approach to addressing environmental justice issues.^{1–3} It emphasizes community involvement in applying scientific knowledge to reduce adverse health outcomes, sometimes through changes in health policy. To date, the process of developing and implementing policy change through CBPR is understudied.⁴ An

evaluation of policy initiatives in four environmental justice projects underscored the importance of strong community leadership, participation, organizational skills, and shared values among partners.¹ Themba and Minkler proposed a multistage process for implementing policy change through CBPR beginning with careful formulation of policy directions. When community partnerships identify and refine common policy objectives, advocating those strategies may be more successful.³

We describe a case study of the policy formulation process in a unique intervention project targeting the intersection of the home and work environment for two economically marginalized populations—low-income elderly and disabled persons and the low-

wage in-home care workers who help them live independently. The on-going study, Partnership for Safety: Making Homecare Safe for All, aims to identify health risks and develop intervention programs to improve health and safety through partnerships between in-home care workers and their clients (consumers) in Alameda County, California. This project demonstrates how alliances among various (and sometimes conflicting) partners within the community could be used to formulate policy directions to improve this challenging home or work environment.

BACKGROUND

Currently 1.5 million in-home care workers in the United States