Exploring Community-Based Research Ethics
Case Study: Healthy Public Housing Initiative

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SECTION 1. Background

Introduction

Current Institutional Review Board standards represent a commitment on the part of the federal government to protect the autonomy and rights of individuals participating in clinical and behavioral research studies. For example, a perusal of the *Belmont Report* of 1979, the foundation upon which current ethics guidelines was built, reveals that its three tenets: respect for persons, beneficence, and justice, are considered only with regard to individual research subjects. As these principles are described in the actual document, they do not address respect for the community, nor do they address beneficence or justice in relation to the community.

This is not to say that protection of the autonomy and rights of human research participants is not of the utmost importance, especially in the context of clinical and behavioral research methodologies. Within a Western social construct, ethical consideration of the rights of persons is a natural extension of a society in which the dominant philosophy is one of individualism. Robert Levine comments on the *Belmont Report*: “It is usually quite appropriate to view investigator-subject relationships as relationships between strangers. Thus, in general an individualistic ethics is appropriate.”

However, the United States is a country composed of a diverse array of ethnic communities, not all of whom adhere to the dominant culture’s individualistic philosophy. In fact, one could argue that individualism is perhaps the antithesis of normal cultural values for many ethnic communities. According to Jillian Inouye, for example, the Asian American population belief system incorporates “kinship solidarity,” which refers to “the view that the individual is subservient to the kinship-based group or family.” John Casken writes: “In contrast to all the Pacific Islander jurisdictions, the United States is basically a classical liberal society” devoid of the traditional community-oriented belief system inherent to Pacific Islander tradition, and thus it is “in reality a social system that is a contradiction to the one in which they were raised.” Hispanic Americans also maintain a similar tradition, familism, which in the context of health care, explains why many Hispanics’ decisions about use of medical treatment or preventative care are family-based.

Moreover, what may be considered ethically beneficial to the individual may not necessarily be beneficial for the community with which the individual is affiliated. Charles Weijer uses two research projects on the genetics of cancer in the Ashkenazi Jewish population as examples. The studies both utilized databanks for Tay-Sachs disease to establish the frequency of a particular BRCA1 gene mutation associated with increased risk of breast and ovarian cancer development. Both studies found that the mutation was more common in the Ashkenazi Jewish population compared to the general population. Because all identifying information had been removed from all samples put into the databank, the NIH Office of Human Subjects Review did not require individual informed consent, as it considered the identities of individuals to be already protected. However, not everyone agrees that the rights of the Jewish population have been protected:

Such findings, which have already led to Jewish groups being targeted as a potential market for commercial genetic tests, could create the perceptions that Jewish people are unusually susceptible to disease…As a result…anyone with a Jewish-sounding name could face discrimination in insurance and employment as companies struggle to keep down health-care costs.

Weijer’s example illustrates how research involving individual members of a larger community, despite good intentions, can have significant repercussions for that community, raising an important issue: “Are
additional measures, above and beyond those currently afforded individual research participants, required to protect communities in research.\textsuperscript{8}

Further complicating ethical discussions regarding community autonomy are the abundant descriptions of what exactly constitutes a community. According to Charles Weijer, the definition of a community is flexible: “we use the word community to describe a wide variety of human associations: ethnic, cultural, political, religious, geographical, municipal, professional, artistic, sexual, and even disease ‘communities’.”\textsuperscript{9} Each association brings to it a unique social dynamic, giving the communities their own personalities and values. Therefore, in developing community-oriented ethical guidelines, one must respect the uniqueness of each community, tailoring guidelines to specifically address the needs of a particular community.

Within an international context, there is an array of literature exploring the ethics of randomized clinical trials in developing nations having different cultural values than the United States.\textsuperscript{10,11} Within both local and international contexts, there are also numerous studies on the ethics of conducting research in communities unified by ethnicity, who therefore share common beliefs, values, and/or politics.\textsuperscript{10,11,12,13} However, very little literature exists on the ethics of conducting research within communities devoid of ethnic and cultural homogeneity and united only by the common thread of poverty.

**Communities within public housing**

Comparison of historical poverty tables with the 1999 poverty data from the US Census Bureau reveals a persistent trend in the disparate distribution of wealth in this country. Black and Hispanic populations have historically been amongst the poorest citizens of the United States.\textsuperscript{14,15} Families from these minority populations, in addition to many other poor families of diverse ethnicities, connected by their socioeconomically disadvantaged status, are brought together by governmental placement, into subsidized public housing developments.\textsuperscript{16} A community is created in these developments, shaped by the distinctive ethnic composition of residents, the needs of the residents, and their interaction with city and development authorities, as well as their relationships with each other. These factors, in addition to the general life experiences of residents, will ultimately impact any research conducted in a public housing setting.

Lorna Ryan emphasizes the dichotomous relationship which inevitably exists between researchers and residents, a consequence of the power differences created by education and economics: “those studied are often in relatively powerless positions, lacking cultural and/or institutional power…the researcher is generally not a member of the community, she or he is generally qualified, with specialized technical language and she or he has the final say about the content of a research report and the dissemination of research findings (largely through the medium of print).”\textsuperscript{17} This complex relationship between researchers and the resident participants in their studies poses ethical dilemmas specific to the unequal power dynamic inherent to any collaborative effort between socioeconomically and educationally ‘wealthy’ researchers and likewise underprivileged residents dependent upon affordable public housing.

**Empowerment through participation**

Many sociologic studies have revealed a strong association between powerlessness (be it from learned helplessness, alienation, exploitation, poverty, or stress) and poor social health status. These studies lend support to the concept of disempowerment (the lack of community empowerment) as a fundamental contributor to unhealthful behaviors such as poor nutrition, high smoking rates, and high alcohol abuse rates – common in minority communities.\textsuperscript{16} El-Askari et. al. posit that “the focus on problem solving by outside experts and systems ‘clientizes’ individuals and decreases their participation in and use of resources from the community, thus weakening community ties.”\textsuperscript{18}
From an ethical standpoint, without active participation of the community in framing research methodologies and the efforts of researchers to educate community residents with knowledge usable in practical application, disempowerment of the community can result, and well-intentioned efforts of researchers may prove temporary. On the part of researchers, there must be “a subtle but fundamental change from focusing on treating the deficiencies of ‘clients’ to working with residents as equal partners and serving as resources instead of diagnosticians.”\textsuperscript{18} Israel et al. define empowerment as “the ability of people to gain understanding and control over personal, social, economic, and political forces in order to take action to improve their life situations.”\textsuperscript{19} According to Lorna Ryan, resident empowerment necessarily requires the development of a mutual respect between researchers and the residents, which acknowledges their differing experiences and perceptions. Researchers must recognize that despite their scientific knowledge, there is much they too can learn from the residents they are working with: “it is the minority ethnic community, the ‘subject’ of the research, who holds the requisite knowledge about cultural practices and views as to appropriate and inappropriate research.”\textsuperscript{20}

While literature regarding community-based research ethics is scarce, there do exist examples from participatory research involving successful collaboration between researchers, residents, city agencies, and community advocates in which useful information applicable to ethical issues can be found. It should be noted that each partner in a collaborative brings to the table specific agendas and personal experiences, and difficulties and conflicts do arise. It is our observation that authors of available literature tend to de-emphasize how the divergence of opinions between researchers and the community can result in heated debate. However, it is the essence of a successful collaboration that misperceptions and clashes of opinion will ultimately result in the mutual education of the research team and the community partners, and a positive relationship forged between all partners, above and beyond the data obtained through statistical analysis.

**Examples of successful collaborations**

One example of a successful participatory research effort is the Neighborhood Participation Project (NPP), a study designed to understand the process of citizen participation in urban Nashville (Tennessee). Researchers worked with members of Sunnyside Community Citizens (SCC), a volunteer neighborhood organization to learn successful ways to help the community discover its strengths and empower itself. They found that education and demystification of the scientific aspects of the project were perhaps of the utmost importance. The research team learned that in this community, a workshop format would be the best mode of education, as it “would allow participants to interact with the research staff and evaluate the data in terms of their own experience.”\textsuperscript{21} Both the participants and research team could learn from each other. “The workshop process would also enable the research team to evaluate [their] understanding and interpretations of the results in the light of citizen experiences and priorities.”\textsuperscript{21} Both the SCC and researchers planned the workshop format together, with the researchers reinforcing the need for equal status between themselves and the SCC: “we did this, in part, by treating them (the SCC) as experts in their own right.”\textsuperscript{22} A relationship based on respect between the research team and the SCC, as well as the participants in the workshop, led to signs of community empowerment, evidenced in a renewed effort to form community groups aimed at specific agendas of concern to the community.

Another example of community empowerment through collaboration is the Lanthrop Homes Beautification Project, in the Lanthrop Homes housing development owned by the Chicago Housing Authority. Ellen Glantz and Lynne Westphal, two professionals, contacted local resident groups and area churches to gain support for the revitalization of greenery around the development. Resident support was key to getting the project off the ground. The result was an enthusiastic formation of the Lanthrop Beautification Committee, consisting of Lanthrop residents, who worked on the planning and implementation of improvements. The project resulted in two residents being hired as paid community
organizers, and further collaboration with other organizations. Environmental improvements have continued through the work of residents and their partners. The authors conclude: “citizens must have control over resources to effect their quality of life.”

The aforementioned examples represent literature currently available on participatory research in low-income, urban minority populations. Our case study is aimed at exploring the ethical implications of collaborative research within underprivileged multicultural public housing communities, using interviews conducted with key staff members from the Boston Healthy Public Housing Initiative (HPHI). The HPHI was chosen because it is a large collaboration, whose roots go back several years to a point when it would have been hard to foresee such a broad coalition coming together around issues of environmental health in public housing. We posit that there are valuable lessons to be discovered in reviewing the disparate threads which coalesced into the present collaboration. Our contribution to the scarce literature available to public health professionals and community members alike about this topic will hopefully serve not only to educate, but also to stimulate further discussion regarding the ethics of conducting research in communities comprised of the poorest members of the United States population.
SECTION 2. The Healthy Public Housing Initiative

Project history

One starting point for the emergence of the HPHI was a participatory cross-sectional survey of health and housing conditions in the West Broadway Housing Development, located in South Boston, in spring 1998. Conducted with funding from the US EPA, approved by the Boston Housing Authority and directed by faculty at BU and Tufts, the “Public Health in Public Housing” project trained staff from the South Boston Community Health Center and residents from West Broadway in indoor environmental health and survey techniques. Together the university and community partners compiled a 150-question asthma/indoor environment questionnaire subsequently administered by paired health outreach workers and trained residents. The results of this survey were publishable, and prompted follow-up programs, such as campaigns to provide window guards and increased efforts to reduce smoking within the housing development.25

The BU and Tufts academic partners in this mini-collaborative were then approached by the Committee for Boston Public Housing (CBPH), a community advocacy organization, to replicate the survey at the Franklin Hill housing development, located in Dorchester. Residents from Franklin Hill were trained and conducted the survey. The results were again compelling and publishable.26 New funding from the EPA, coupled with data from the Franklin Hill survey prompted a pilot asthma intervention study at Franklin Hill, and further expanded the collaboration. Tufts, CPBH, and environmental scientists from Harvard worked with the Franklin Hill tenant association to test the usefulness of environmental interventions, generate pilot data, and study asthma triggers.27,28

The HPHI, which began in January 2000, is a culmination of formal meetings amongst the universities, community partners, city agencies and resident associations involved in the first pilot studies, who have worked toward expanding the scope of their efforts. The HPHI is led by three public health degree granting institutions in Boston: Boston and Harvard University Schools of Public Health, and Tufts University School of Medicine. The community partners involved are the Committee for Boston Public Housing (CBPH) and the South Boston Community Health Center (SBCHC), and the West Broadway and Franklin Hill tenant associations. Also joining the HPHI are two city agencies, the Boston Housing Authority and the Boston Public Health Commission. Two consultants, Peregrine Energy and Urban Habitat Initiatives, advise the project on energy and housing policy/finance.29

We emphasize that the HPHI is a large collaboration, and it did not happen without extensive dialogue. There were considerable areas of difference between the organizations that needed to be hammered out. These included the nature of decision-making, the equitable apportionment of future funding, the scope of work, and who would be at the table. These were not simple discussions since the partners had vested interests that were not easily compatible. As an example, the Boston Housing Authority (BHA) had very different views from the tenant associations, as to be expected when the BHA owns the developments of which the tenant associations are a part. However, their familiarity with tackling such substantive issues allowed them to more easily resolve their differences than might be expected in the resident-landlord relationship.30

Other members of the HPHI also found that they had conflicting areas of interest and were less familiar with each other. The three universities have traditionally been competitors and were not used to this kind of collaboration. Appointing a faculty person from each university as a co-chair of the project helped to lessen the strain in this regard. Likewise the community partners were skeptical of the universities, whom they regarded as relatively wealthy institutions that might not give them a fair share in the budget. Long and sometimes arduous meetings were necessary to work through the budgets in detail so as to satisfy community and university partners, a process that drives up the total budget for the project
and reduces the scope of work possible under partial funding. Even the two city agencies had to adjust to each other when the collaboration chose to seek funding from HUD on the same Notice of Funding Availability for which Boston Public Health Commission had already been preparing an application.30

However, despite their differences, collaborative members, throughout the planning phase of this project, have been able to unite around a common goal of creating healthier public housing--residents, buildings and communities.

Learning through experience

There have been several lessons learned from our experience, as well as many more lessons to come as the HPHI project timeline progresses. First, the smaller pilot studies conducted by various subsets of partners facilitated building a large joint project. Second, there is no substitute for learning to work together in practice and resolving tensions through day-to-day common experience. Finding common ground within such a diverse coalition requires constant attention to the different needs and interests of the assembled groups and individuals, something that continues today in an ongoing way. Third, a collaboration that gives generous time to the discussion of study design will benefit from the informed and grounded suggestions of community partners. These benefits accrue to the outreach process, response rate, relevance and clarity of questions, selection of interventions, and involvement of residents.30

A fourth lesson is that each prospective party to the joint project has to decide that they have more to gain than they lose by whatever compromises they make to become a part of the team. Fifth, the processes of writing substantial grant proposals and entertaining site visits from possible funders, despite the energy drain that they represent, also provides opportunities to work through problem areas. Sixth, all partners need to be prepared to bend but not break. They have to feel free to raise concerns and disagreements while maintaining constructive relationships with the rest of the project. Lastly, it is critical that all parties keep one eye on the central aim of our work, that is to improve the lives of people living in public housing and to remember that we have a better chance at doing so together than apart. As the adage goes, our strength is in our unity.30
SECTION 3. INTERVIEWS

Methods

Key informant interviews were conducted with 14 individuals who are staff or students at one of the 11 organizational partners to the Healthy Public Housing Initiative. Two interviews were excluded from further analysis. One was staff at a community partner who did not have enough direct experience with the project to comment on many of the questions, the other was a student with limited contact with the project. Individuals were recruited such that we included representation from academic researchers, community partners, the city partners and consultants to the project.

The interviews consisted of 4 demographic questions and 12 questions pertaining to ethics of community-based research (Table 1). All interviews were conducted by one of us (AK) either at Tufts University School of Medicine or in the community. Each person interviewed signed a consent form that assured him or her that their name would not be associated with their comments. Interviews were audio taped and transcribed verbatim by several undergraduate students who received training in research ethics prior to listening to the interviews. One of us (DB) did a content analysis without blinding as to the identity of the interviewees because it was obvious to him who they were just from what they said and how they said it. The analysis did not attempt to generate quantitative or generalizable information, but rather to note key themes and ideas that emerged from the interviews. Themes were coded and analyzed by question. The Tufts IRB approved the protocol.

Demographics of interviewees

Interviewed were five people who were from the community partners, two from the city agencies, two who were consultants to the project and three who were researchers. Ten of the 12 interviewees were white. The average years in any type of research was 8.54 (SD 6.79) with a minimum of 0 years and a maximum of 20 years. Interestingly, the interviewees with the most years in research were a consultant and a community person. This was perhaps because the project directors were not interviewed due to scheduling limitations. The average years in community-based research were lower, 5.00 years (SD 6.19) with a range of 0 to 20 years. Average years involved in the community outside of research was 16.25 (SD 11.69) with a range of 0 to 40 years. The community interviewees had substantially more years of involvement in community work (average for community interviewees was 24.40 years; SD 13.32).

Emergent themes

Question One. What are the three main benefits to the community which can be gained from community-based research which make this type of research unique compared to other types of research?

There was broad agreement among those interviewed about the benefits to the community. The most frequently cited benefit was bringing added resources (including money, skills and knowledge) to the community. Another frequently cited benefit was that the research could provide the community with data that it needs to advocate for itself. This was stated as, “confirmation that certain conditions cause certain health problems” by one community interviewee. Also noted were the possibilities that the researchers would ask better questions because they understood the community and that the community would understand the research process better for their participation. Mentioned by single interviewees were more emphasis on qualitative information and learning about community assets (instead of community problems).

Question Two. According to the IRB, the principle of protecting research participants is defined as beneficence. Beneficence is upheld by researchers who follow two general rules: “do no harm” and
“maximize possible benefits and minimize risks” (Belmont Report, 1979). How do researchers protect the participants in community-based research from harm and secure the well-being of their participants?

Most interviewees thought that there were distinct ethical concerns in community-based research that did not exist in other types of research. However a small number of interviewees (two community members and one researcher) either thought there was no difference or listed only concerns that seemed to apply across traditional research as well. Stated most strongly the researcher said, “I think this is no different than any other type of research.” A couple of other interviewees listed common concerns, such as dangers of going door to door and informed consent, as well as concerns distinct to community-based studies.

Three interviewees thought that active involvement of community members/organizations would lead these groups to defend the community and protect their interests. Others stated a related theme that seemed to be based on the same concern. They said that there needed to be equality between researchers and the community or that the community needs to have a voice and be involved as much as possible or that two-way communication was important. One community member suggested that honestly involving the participants might result in them being more truthful with researchers and also thought that the results needed to be reported back to the community. Two interviewees, a consultant to the project and a community member, used the phrase “lab rats” to describe what the community must not be in the research process.

Three interviewees pointed out that there were methodological issues with respect to having community members survey their own community. A community member and a consultant to the project both indicated that privacy might be more important because the interviewers and interviewees know each other. A city staff person said that research methodology is at odds with what makes sense to the community.

One community member discussed the problem of “unflattering data” and “blaming the victim”. But this person went on to say that, “on the other hand, I think one of the important strengths of the community themselves no matter what the sources are, whether they are institutional racism, or cultural, historical forces or whatever, people can begin to feel better if they uncover the data, if they’re asking the questions.” This same person also commented on the need to ask the right questions and the ability of the community to contribute to formulating such questions.

The risk of not meeting expectations was raised by a city staff person and two interviewees pointed to the need for tangible benefits to the community to come out of the research.

Question 3. Informed consent represents a trust, between researcher and participant, that the participant has been honestly informed of all the risks and benefits of the study. How do you think the concept of trust and honesty can be expanded to encompass the relationship between researcher and community?

Three interviewees raised a concern about defining what is the community and how can it have trust. “I am not sure that the community is an entity that can have trust,” stated the researcher who thought informed consent should be with individuals. A consultant observed that, “a community ... is very broadly defined and is a very nebulous thing in most cases”. A community member wondered, “How would you know what the community thinks about us [the project]. I mean would you take a poll? .... Would you let elected officials speak for the community?”

Three interviewees pointed to involvement of community organizations as key and one community member noted that that “didn’t happen in the Healthy Public Housing” until, “community oriented people stuck to their guns and insisted on the involvement of community groups.” Four interviewees raised
relationship building in one fashion or another. One consultant spoke of “breaking bread” together. A city agency staff person talked of the years of smaller scale projects that were needed to lay the basis for the current project, saying, “it took [two of the project directors] a while to get in, they had to talk to the right people at [the agency] who were willing to put aside their fears ... of headlines about them.”

One community member suggested that it would have been helpful if the universities had had a presence in the communities, “offering classes” prior to requesting a partnership around research. Four interviewees, two researchers and two from the community thought that honest (even brutally honest) clarity about what researchers want to do is needed. Also raised were the need for the community to get something back from the research, being willing to “stand down” from ideas you think are right in order to get to a middle ground, the need for recognition that the researchers don’t necessarily know about community problems, that monetary payments as the sole incentive don’t work and the need to allow for the possibility of little ideas “dinging up” out of people’s lived experience.

**Question 4. When thinking about the ethics regarding the publication of data, what are the main considerations researchers must think about when doing community-based research which are different from doing other types of research?**

Six interviewees expressed concern about privacy or confidentiality. One city staff person restated the contrast between research anonymity and the need for openness in an organizing model, saying, “in a community benefits model you want people to identify themselves.” A researcher, concerned about small sample sizes said that, “if you are publishing a study of 100 households in a single [public housing] development it is possible for people to see who was involved.”

Two interviewees, community and city agency persons, thought the key to publishing data was simply sharing it back in a way that is accessible. Six interviewees, however, expressed concern that results showing that housing conditions were negatively affecting resident’s health could be used in the policy arena to divert support away from public housing rather than to fix it up. Said a researcher, “the community has been concerned that politicians seeing the research would say that they should take their money out of public housing because it is just making kids sick.”

The conclusion that five interviewees came to was that there was a need to “take a political stand” or present data “in a positive spin” instead of simply stating findings and walking away. Interestingly, only one of the persons stating this position was from the community, the rest being, two researchers, a consultant and a city staff person.

Other issues raised by single interviewees were ownership of the data, focusing on interventions rather than documenting problems, being careful not to “embellish” data, the value of publishing this type of research in medical journals alongside clinical trials, looking to see where money is going in the budget and acknowledging participant’s, “who actually worked hard in the process”.

**Question 5. What are the ethical responsibilities of researchers involved in community-based research that are different from clinical or behavioral researchers, for example?**

Four interviewees, each from a different sector, noted the need for adherence to traditional ethical frameworks, such as informed consent, confidentiality and doing no harm. Four interviewees raised questions about how the research would benefit the community. One community member compared community-based research to clinical medicine in that, “you get some obligations over time” and observed that service and research may both be a part of community-based projects.
Two interviewees, one a researcher and the other a community member, brought up concerns about the influence of money given to research participants who are poor. The community member said, “say that we are doing the survey and you are not clear as researchers what are their motivations. Say that we are paying them to do the research, how do we know the information we get is really valid? Or the people are just in it for the money because they are poor.” This person went on to suggest that respondents might also slant their answers. Two other researchers emphasized the need for adherence to conventional research methods. One pointed out the need not to give away the hypothesis in certain situations. The other stressed that the data had to be “correct and objective” and that you have to be sure that “no information is being fudged”.

Other points raised included a comment by one of the consultants that, “this is so unique and the fact that all these people are around the table on an issue. A lot of these people have not been around the table on an issue before and it just amazes me on a daily basis to see some of those individuals at each other’s throats in various fashions trying to work things out. It has not been easy.”

One community interviewee thought that more anecdotal information from focus groups was good. Another community member thought there should be a support group for researchers doing community-based research. This same person asked that researchers behave as allies to the community, that they check their defensiveness at the door and that they not pretend that they have no agenda. A different community interviewee thought that the main thing was getting to know the community because, “it [can] actually turn out to be very different than what you thought”.

**Question 6. What are the ethical responsibilities of community partners involved in community-based research?**

There was strong sentiment that the community should protect the community and represent its interests as expressed by seven interviewees from all sectors of the project. But most interviewees did not leave it at that. Balancing the other roles of the community partner was expressed as also obtaining valid answers and serving as a liaison between the community and researchers.

Two community interviewees explicitly addressed the limits placed on them by forming a partnership. One noted that, “you can’t both accept to work with the university and then be mad when the university acts like a university.” The other told of having to “water down” a public statement because of being in the collaboration with the city agencies who were nervous about lawsuits and observed that while it made sense to make the trade-off, that there was a “price to pay”. This person thought the community had to ask, “When is it a good time to collaborate?” Three other interviewees mentioned partnership issues, but not in as much detail.

Two interviewees, both with the city, thought that funding arrangements with the community raised ethical issues. One said, “Funding drives a lot of things, but I would hope that people don’t just sit at the table and look at the immediate funding needs and resources”.

Other points included the community making sure that the right questions are asked, that they follow the data where it leads, that they be responsible for the commitment they made, that they serve as a source of information and data, that they be honest about their agenda, that they ask what the researchers are doing and learn about the research process, and that they think about how the research might be used. One community member thought that the first Policy Advisory Council meeting of the project was too research focused and did not focus adequately on the community.
Question 7. What are the ethical responsibilities of the city partners involved in community-based research?

Both city agency staff that were interviewed expressed strongly and with some detail the idea that it was the responsibility of their agencies to, in the words of one, “effect policy changes based on research.” One of these interviewees went on to point out that the universities do not have the power or mandate to implement such changes. Two other interviewees, both researchers, also noted, with less emphasis, that the city is the place where policy changes would happen based on the research findings.

Three community interviewees commented on how political the city government is. Stated most strongly, this was expressed as, “They don’t want to make the administration look bad, so I think that it’s hard for them [city agencies] to generate data that reflects on current policies or even generate information that reflects on previous policies.” Two researchers and, to a lesser extent, one community interviewee, were concerned that residents participating in the study not be put at risk if they were found, in the course of research, to have violated their lease.

Other ideas that came up were, that the city has a broad responsibility to provide “safe and decent” housing, that the city must give equal access to health services and information, that it must strive to serve the lowest income households, that the city not go into the project in order to raise money for itself and that they had, in the words of one researcher, “a very strong ethical obligation” to share as much data as possible.

Question 8. What does the term “good science” mean from a community-based research perspective?

Responses to this question were mostly along two themes. One was that good science is science that provides practical benefits to the community. The other was that good science is defined by adherence to research techniques. Seven interviewees, 4 from the community, two city agency staff and one consultant defined good science in terms of what it gave back to the community. One community interviewee said that good science is, “science that the community can benefit from by learning something new about themselves and use it as a tool to improve [the community].” One of the city agency staff and the consultant seemed to suggest trying to balance the community benefits with academic purpose, but did not get into issues of research technique.

One interviewee from the community simply said that good science was no different when applied to community-based research and did not elaborate further, which may imply support for measuring science primarily by its adherence to traditional methods. All three researchers, however, were unambiguous in their concern about research methods. One considered the main criteria to be whether a study is replicable. Another re-raised the issue of not telling participants what the hypothesis is. The third, saying, “I think that a lot of the rules of good science still apply”, pointed to testing a hypothesis as critical.

The third researcher, however, also spoke about how community-based research raises questions, presumably in the minds of other researchers, about the “objectivity” of the work and concluded, “some might say that you don’t necessarily have good science, you have standard observation.” The second researcher raised a point, perhaps related, in saying that, “this is research [community-based] at its infancy” that still needs to develop new techniques. Perhaps the idea here is to find ways to bridge the gap between community and researcher needs that retain objectivity and validity.

One of the community interviewees related an experience in which researchers not affiliated with the HPHI apparently tested a research method in the community without giving much back. This community member thought that that was “inappropriate” and that it, “caused all sorts of problems”. This same person noted that the earlier pilot study by one of the directors of the HPHI was “pretty good”. Also
raised by this interviewee were having a reasonably good chance of finding something, not deceiving participants (apparently in direct conflict with the researcher who suggested withholding the hypothesis), asking researchers to ask whether they would allow this to be done to them and pointing to issues of class, race and gender as factors to take into consideration.

**Question 9. From an ethical standpoint, what defines success in a community-based research study, with respect to study outcomes?**

The most common answer to this question was that the community/residents see improvements as a result of the study. Seven interviewees from all sectors of the project said something to this effect. There was clearly more convergence and overlap on this point than in answering the question on “good science”. Five interviewees, again from various sectors, thought that the process of building the partnership and seeing it grow and be able to continue was an important measure of success. Four interviewees, the three researchers and one of the agency staff people, also defined success in terms of data outcomes. Only one of these, a researcher, listed data outcomes as the sole measure of success.

One city agency staff person noted that the earlier pilot studies helped the agency take up the issues that the HPHI is aiming to address, namely housing conditions and health. This person said, “the data was quite alarming and brought a new level of focus to the issue.”

**Question 10. Describe how you feel about what defines the appropriate relationship between researchers and participants? What defines the appropriate relationship between researchers and the community?**

The words respect or mutual respect was stated explicitly by only five interviewees, but almost everything raised seemed to implicitly rest on a foundation of mutual respect. Eight interviewees spoke about relationship building, sometimes using those words and other times being more descriptive. All five community interviewees addressed this theme; the other three were a researcher, a consultant and a city agency staff person.

Some of the ways that relationships could be built interviewees, included allowing the “other person” to not be perfect, make no assumptions about who participants are, that researchers must remember that they are not part of the community, being aware that “I am in someone else’s home”, maintaining boundaries, being aware of the power “gap”, and getting involved in the community. A city staff person said that, “a researcher [should] not [be] pretending to befriend someone on the street because they are trying to do a survey.

Honesty, equity and clear communication were also raised by six interviewees from all sectors. Three people, one from the city and two researchers noted that either the researchers could provide training to the community or that the community had a lot to teach the researchers. One city staff person mentioned “producing” on confidentiality and a consultant wanted to know how does one define community, is it the housing development, the surrounding neighborhood or all of public housing in Boston?

**Question 11. Thinking about the IRB training you completed, name 3 amendments you would like to see added to the text, which would educate readers on the ethics of doing community-based research?**

Unlike any of the other questions asked, this question resulted in three interviews without answers, one interviewee who said they did not have an answer and another who said that the IRB did not have a role in setting ethics guidelines, but rather only in enforcing them. Also, unlike answers to other questions, the remaining answers did not coalesce into clear themes. Instead they are more of a laundry list, with no one mentioned by more than one interviewee.
Possible additions to the IRB training, in no particular order, were: “maybe something about how the information is going to be used at a community level” and how to treat unflattering data; that the IRB is too “after the fact” and too focused on punishment instead of caring, concern and humanity; “it’s truly the institutions protecting their butt”; to not use the word subject because you are not studying specimens; that the medical model limits the ability to promote and that confidentiality is not always applicable; that it takes time to get to know a community; that there were “lots” of researchers seeking to study people in Boston; to make sure you understand the pressures on research participants; to clearly understand the actions that will result from the research; that if you are working with several community partners you will need many meetings for problem solving; to always maintain a professional manner with participants. One researcher said that the project should do what “is best for the participants and not necessarily what is in the best interests of the project.”

**Question 12a. What is the appropriate ethical approach to a situation in which a tenant participating in a research project is found to be engaging in activities considered to be in violation of their contract with the landlords?**

There was broad agreement on this question. Eight interviewees said that the project should ignore tenant violations of their contract with the landlord. None of the remaining four interviewees fully disagreed. One did not answer, one pointed to things the housing authority was not doing, and one though the project should have a plan. The final person thought people dealing drugs should be evicted.

**Question 12b. What if the researcher witnesses evidence of intentional injury to a child from a participating apartment?**

There was general agreement that this situation was different from that in question 12a and that looking the other way was not an option. Six respondents from all sectors of the project thought that child abuse had to be reported. Three of these people said that they were mandated reporters anyway. Five interviewees thought that something had to be done, but were uncomfortable reporting to authorities. Said, one, “sometimes the system to address it could be worse”. These five tended to think that the project should report to an “intermediary” or third party, although their ideas of who that would be were generally vague. The remaining respondent said only that the project should have a plan in place.
References


30. Brugge, Doug, et.al. *Building a City-University-Community Partnership for Healthy Public Housing.* (draft for submission).
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<th>Table 1. Interview questions.</th>
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<tbody>
<tr>
<td>1. Sector (community, city, research, consultant)</td>
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<td>2. Number of years in research</td>
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<td>3. Number of years in community-based research</td>
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<td>4. Number of years involved in the community</td>
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<tr>
<td>1. What are the three main benefits to the community which can be gained from community-based research which make this type of research unique compared to other types of research?</td>
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<td>2. According to the IRB, the principle of protecting research participants is defined as beneficence. Beneficence is upheld by researchers who follow two general rules: “do no harm” and “maximize possible benefits and minimize risks” (Belmont Report, 1979). How do researchers protect the participants in community-based research from harm and secure the well-being of their participants?</td>
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<td>3. Informed consent represents a trust, between researcher and participant, that the participant has been honestly informed of all the risks and benefits of the study. How do you think the concept of trust and honesty can be expanded to encompass the relationship between researcher and community?</td>
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<td>4. When thinking about the ethics regarding the publication of data, what are the main considerations researchers must think about when doing community-based research which are different from doing other types of research?</td>
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<td>5. What are the ethical responsibilities of researchers involved in community-based research that are different from clinical or behavioral researchers, for example?</td>
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<td>6. What are the ethical responsibilities of community partners involved in community-based research?</td>
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<td>7. What are the ethical responsibilities of the city partners involved in community-based research?</td>
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<td>8. What does the term “good science” mean from a community-based research perspective?</td>
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<td>9. From an ethical standpoint, what defines success in a community-based research study, with respect to study outcomes?</td>
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<td>10. Describe how you feel about what defines the appropriate relationship between researchers and participants? What defines the appropriate relationship between researchers and the community?</td>
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<td>11. Thinking about the IRB training you completed, name 3 amendments you would like to see added to the text, which would educate readers on the ethics of doing community-based research?</td>
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<td>12. What is the appropriate ethical approach to a situation in which a tenant participating in a research project is found to be engaging in activities considered to be in violation of their contract with the landlords? What if the researcher witnesses evidence of intentional injury to a child from a participating apartment?</td>
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