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Ethical Engagement of Communities, Institutions, and Providers in Research: Lessons From the Community

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This is the story of the Bronx Research Review Board, or as I affectionately called it, the CRAB. It is told from my perspective with honor and credit duly given to the men and women who helped to bring the dream of a community research board to fruition. This is written to provide guidance to those who plan to create community research review boards in neighborhoods, cities, and communities where there is a need to take action to control what, how, when, and for the benefit of who, research is conducted. We wanted more than just an alternative to the institutional review board (IRB) . . . we wanted to create a platform for the education of community residents, staff, and researchers where all could engage in a “problem-posing” approach to research. By creating this critical pedagogy, we wanted to link knowledge to action so that we would all actively work to change our community—by street, neighborhood, and beyond. What follows is the story of how we tried this novel approach to community development and education, where participants are not passive recipients of knowledge but become true and empowered partners in a process of change. This commentary is offered as an alternate, more personal account of the Bronx Community Research Review Board. The CRAB became my mission, my passion, and ultimately my saving grace because it created a space where it was possible to imagine the possibilities for something much better for my most beloved community.

WHY A COMMUNITY REVIEW BOARD IN THE SOUTH BRONX

For some, the South Bronx will always be a smoldering urban wasteland; however, it has always been more than that to those who live, work, and struggle there. We wanted to acknowledge and utilize an assets-based approach to the

development of the CRAB, recognizing what the community brought to the table, assist them in understanding their strengths, and build on that to engender a dialogue for community development. *The Belmont Report* established three major ethical principles—respect for persons (or autonomy), beneficence, and justice. Emanuel and Weijer note that the word “community” does not appear in *The Belmont Report* and argue for a fourth principle to be added—respect for communities. They believe that a community ought to be accorded moral status over and above the respect owed to individual community members. They propose protections by consultation in research protocol development, providing and obtaining informed consent (at both individual and communal levels), conducting the research, gaining access to data, and disseminating findings.

Therefore, we started with a view that communities are to be respected, that they are complex, and that research could not engage vulnerable groups without according them special consideration. We also acknowledged that the issue of prior abuses—both real and perceived—exist in these communities and had to be addressed as a starting point to the work. We also defined community in broad strokes, going beyond the professional elite so often represented on boards, to a more representative community that envisioned inclusion of the poor, the less educated, and the marginally employed. The starting point was accepting the diversity of the community and ensuring that they were represented on the Board. The CRAB was intended as a structural approach to achieve community consultation in research. It would also create a platform for discussion about what research is needed to serve the community and meet its self-identified needs.

SITE VISITS, LITERATURE SEARCH, AND PROCESS

The CRAB was conceived as voluntary body that would serve a consultative function and would collaborate with the Albert Einstein College of Medicine (AECOM) IRB. Investigators seeking to conduct research in the Bronx would present their proposed research to the board and thereby open a face-to-face dialogue about community perspectives that would strengthen cultural appropriateness in the proposed research and alert investigators to community sensitivities or concerns. The board would engage in open discussion with the investigator and offer advice on recruitment, incentives, sensitivities, and effective communications. Investigators would be expected to return to the board to discuss major revisions and present their findings at the conclusion of their research. Ideally, the board would work toward consensus and provide guidance and in some cases raise “community concerns.” Use of the CRAB would convey to the investigators and others the unique process of community consultation that they had pursued and their commitment to the protection of individuals and communities.

THE BRONX CRAB SELECTION PROCESS

We recruited and then interviewed prospective members utilizing a group deliberation process. We developed all the processes and reported on outcomes and products with no involvement by our AECOM partners. Although in hindsight the freedom from intervention from the academic partner was liberating, we also missed many opportunities to engage the AECOM staff and faculty, who might have offered recommendations. A true partnership requires discussion of ideas and engagement in the development of a mutual product. Rather than engage in a participatory process, each party operated in a void with little communication, discussion, or consensus building.

The original plan for the CRAB envisioned a mechanism for community consultation for all research conducted by a specific set of AECOM trainees. These investigators were chosen for several reasons, but of note was the belief that the trainees would learn through this experience and that would have a powerful effect on their research careers. Thus, as written in the original proposal, this approach would create a “domino effect,” impacting the culture of research in the future. As the board matured, the plan was to have it review

proposals from non-trainee investigators and from institutions other than AECOM and Montefiore Medical Center. There was never an accountable process, resulting in no one being aware of what was going on, who was doing what, and why. The same distrust that we were trying to address was maintained by a process where there was no clear designation of roles and responsibilities.

DEVELOPMENT OF A TRAINING PROGRAM UTILIZING THE PAOLO FREIRE

We agreed that the participatory nature of CBPR was a good first step, but believed in the more political goals of Popular Education. The purpose of Popular Education is *conscientization* or the cyclical process of people joining with peers to name their world by critically reflecting on the socioeconomic and political conditions they exist in. It is a goal of popular education that the participant emerges from the oppressor–oppressed dynamic to create a new way of looking at the community and working to improving it. Our goal was to create the infrastructure for facilitating community involvement in reviewing research and influencing the research agenda of our academic partner by identifying topics that are considered a priority in the community.

Using the Freire principles links knowledge to action so that participants actively work to change their societies at a local level and beyond. A predominant feature of Freire education is that people bring their own knowledge and experience into the process. We created training sessions that started with a communal meal, often chosen by the participants; in this communion, participants discussed current events, bonded, and created a safe space. We also engaged in a popular education activity and dedicated each session. Each of the sessions lasted for 3 hours and the ethics session was facilitated by an experienced facilitator.

LESSONS LEARNED

1. *Veracity*: There was a conceptual agreement with no real actualization on a shared vision for the work between TBHL and AECOM yet at the end, you had three silos with the CRAB caught in the middle of an ideological war between the two primary partners. There should be clearly stipulated expectations, a contract or memorandum of understanding clearly delineating the rights and

responsibilities of each party to this type of work, and the designation of an outside arbitrator or negotiation process when there is disagreement.

2. *Limited funding*: It is impossible to have an equitable relationship when one entity in the partnership receives the lion's share of the funding. It is difficult to talk about equity when there is no equality in funding.
3. *Sustainability*: The original funding for the CRAB ended and, although arrangements have been made to continue funding, monies must be enough to ensure independence and sustainability.
4. *Use of Paolo Freire's Popular Education* is recommended for those research review boards that will bring in community members from diverse educational backgrounds. Using the model of Popular Education is based on using the knowledge and experience that the members bring into the process on relies less on professional and educational credentials.

CONCLUSION

Our vision was for an independent, self-sustaining community research review board to provide access to community consultation, awareness, and engagement. We anticipated that the CRAB members would move on to become community or non-affiliated members of other IRBs and speak out and advocate for acceptance and appreciation of research that respects and engages communities. We also wanted CBOs to develop the capacity to assist in adding much-needed rigor and cultural relevance to community health research, and engage with local researchers in a more structured and systematic dialogue. The CRAB is a work in progress, but it continues as a testament to those who came before us and those who will continue it in our absence.

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