



# **Towards New Ethics Protocols for Community-Based Research**

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and

# **Community Research Ethics in Red Hook**

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## **Abstract**

The first piece, “Towards New Ethics Protocols for Community-Based Research,” serves as a brief introduction and templates for community-based research protocols, based on three different scenarios: 1) for researchers working with an established group or organization, 2) for researchers working with community members, and 3) for researchers who are just one of several (or many) researchers working with the same community. The second piece, “Community Research Ethics in Red Hook,” serves as a community response—one that articulates how Red Hook Initiative has developed strategies for negotiating research ethics and maintaining the power of local residents in relation to research. Together, we hope to prompt more sustained conversations, to collectively work towards research protocols that treat community members as participants and co-thinkers rather than subjects, and that achieve “clarity through specificity” on good practices for reciprocity and accountability.

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## Towards New Ethics Protocols for Community-Based Research

Celina Su<sup>1</sup>

### Summary

The National Research Act of 1974 established our current system of university-based Institutional Review Boards (IRBs) in order to ensure truly informed consent and protections of human subjects in biomedical research. This system of IRBs regulates low-risk, social research as well, imposing what some scholars have critiqued as ill-fitting medicalized, paternalistic, individualistic assumptions on community-based research (CBR). In the meantime, many of the most common issues raised by community members in CBR—resentment and research fatigue (when researchers ask participants the same questions again and again, rather than questions prioritized by communities), “drive-by” research by students abiding by academic timelines—remain unaddressed by IRB reviews. Practically speaking, what should research ethics reviews regarding data collection, analysis, co-authorship, dissemination, and ownership of data look like in CBR and activist scholarship?

Here, we present a brief introduction and templates for community-based research protocols, based on three different scenarios: 1) for researchers working with an established group or organization, 2) for researchers working with community members, and 3) for researchers who are just one of several (or many) researchers working with the same community. With this piece, we hope to prompt more sustained conversations to collectively imagine and articulate what alternative, community-based IRBs might look like—for research protocols that treat community members as participants and co-thinkers rather than subjects,

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and that achieve “clarity through specificity” on good practices for reciprocity and accountability in CBR. We draw upon both our own firsthand experiences and past URBAN convenings and discussions that brought together researchers and activists from within and outside academia.

## Introduction

“Nothing about us without us!”<sup>2</sup> This demand speaks to a core principle of Community-Based Research (CBR)—that research and policies focused on specific communities should not be implemented without meaningful input from and collaboration with the ultimate stakeholders.

CBR and related methodologies (such as Participatory Action Research (PAR), Community-based Participation Research (CBPR), Appreciative or Asset-Based Inquiry, Collaborative Inquiry, and Practice-Based Research) have gained considerable traction in the social sciences over the past few decades.<sup>3</sup> However, ethical research protocols and informed consent practices have not kept pace with increasingly frequently implemented and continually evolving CBR practices. Most university-based research ethics boards (also called institutional review boards, or human subjects review boards) focus on ethical dilemmas common in biomedical research in laboratory settings, with less attention to social research in the field, especially in projects where community members are themselves considered producers of knowledge. Further, some researchers lament that as participatory methodologies have gained legitimacy, “PAR” has also become a “buzzword turned fuzzword,”<sup>4</sup> a label that researchers have used for projects employing qualitative or ethnographic methods even when they treat community members as traditional subjects and informants, rather than collaborators.

There is a need, then, for researchers to consider alternative research ethics protocols that consider what meaningful, context-appropriate CBR methodologies might look like. In spring 2017, the URBAN Research Network New York node, Public Science Project, Racial Equalities group, and Gittell Collective gathered a small group of university-based academics, community-based researchers, and community activists to discuss key questions and practices that center the ethical considerations & needs of communities, rather than academic institutions, in public scholarship.

This report builds upon that meeting and additional research and conversations with community-based organizations and social movement groups, to suggest potential memoranda of understanding between academics and

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<sup>2</sup> Davies, Norman (1984). *Heart of Europe: The Past in Poland's Present*. New York: Oxford University Press.

<sup>3</sup> See, for example, Nina Wallerstein and Bonnie Duran, "The Theoretical, Historical, and Practice Roots of Community-Based Participatory Research," in *Community-Based Participatory Research for Health*, (eds) Meredith Minkler and Nina Wallerstein (San Francisco: Jossey-Bass, 2003).

<sup>4</sup> Pablo Alejandro Leal, "Participation: The Ascendancy of a Buzzword in the Neo-Liberal Era," in *Deconstructing Development Discourse: Buzzwords and Fuzzwords*, (eds) Andrea Cornwall and Deborah Eade (Oxford: Oxfam, 2010).

communities in CBR. We hope that community-based researchers, community-based organizations, and community members find this report useful and use it to engage in constructive dialogues on research ethics and collaborations.

### A need for new research ethics protocols

Revelations regarding unethical research, including the infamous 1932-1972 U.S. Public Health Service Tuskegee study—in which hundreds of African American men with syphilis were never informed of their contraction of the disease, nor treated, even after the development of successful treatments—resulted in the National Research Act of 1974.<sup>5</sup> This act established a system of Institutional Review Boards (IRBs) based in universities and other institutions, to ensure truly informed consent. While such IRBs aim to protect participants in social science research, they tend to emphasize ethical questions commonly raised in biomedical research conducted in laboratory settings, as mentioned above. More subtle ethical dilemmas, like those more commonly raised in social research and fieldwork, often remain unaddressed. In fact, some academics have suggested that IRBs impose ill-fitting medicalized, paternalistic, and individualistic assumptions in research ethics to community-based social research (see, for example, Noorani *et al* and Brown *et al*).<sup>6</sup> Some IRBs also work to protect universities' legal interests and assert ownership of research findings as intellectual property; this stance flies in the face of CBR ethical principles of collective ownership of data and co-production of knowledge.

*In fact, some academics have suggested that IRBs impose ill-fitting medicalized, paternalistic, and individualistic assumptions in research ethics to community-based social research.*

In the gatherings that helped to shape this document, participants raised several foundational concerns. First, activists expressed being wary of colonizing, extractive models of research, and of past problematic research practices in their communities. In particular, they repeatedly raised questions of “drive-by” or “helicopter research,” in which scholars (often doctoral students) collect data for a

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<sup>5</sup> For an introduction, see the Centers for Disease Control web page on the Tuskegee Study, at <https://www.cdc.gov/tuskegee/after.htm> (accessed October 2017).

<sup>6</sup> Tehseen Noorani et al., "Participatory Research and the Medicalization of Research Ethics Processes," *Social & Legal Studies* (2016), p. 0964663916677561; Phil Brown et al., "Institutional Review Board Challenges in Multi-Partner Community-Based Participatory Research," in *American Sociological Association Annual Meeting* (Boston 2008). Internationally, too, most human research guidelines tackle use of human materials, embryos, and data collection in biomedical research. For the 2018 International Compilation of Human Research Standards, see <https://www.hhs.gov/ohrp/sites/default/files/2018-International-Compilation-of-Human-Research-Standards.pdf>

short academic year and never return to even report their findings.<sup>7</sup> They also questioned the cultural competency of research teams, and whether the study design was appropriate for the specific community context. Some activists expressed “research fatigue,” stating that they are tired of answering the same questions again and again (driven by academic and foundation priorities). They questioned why significant questions and their prioritized research agenda remained unexplored, and why research timelines tended to abide by academic calendars and publication deadlines, rather than practice-, campaign-, and policy-focused timelines as well. Most of all, they raised concerns regarding time and labor.<sup>8</sup>

Second, activists emphasized that instrumental and normative concerns are irrevocably interwoven in CBR. They valued community-based research not only because it often helps to produce higher-quality research, or because it bestows certain types of legitimacy upon both researchers and communities in collaborations, but also because it shares power and treats them seriously as co-thinkers. Sure, compared to traditional, hypothesis-testing research, CBR can allow researchers to collect more nuanced disaggregated data, to trace a greater range of possible causal pathways and theories, and help to surface or produce higher-quality responses and policy implications in social research.<sup>9</sup> But participants in the convening asserted that community members also have a *right* to research—to gain strategic knowledge—and engage in intellectual pursuits themselves.<sup>10</sup> They wanted to assert the right to not just provide higher-quality data, fine-grained details, or personal stories to research, but to co-interpret the meanings, themes, and causal theories as well. Research should not remain the domain of university-based academics.<sup>11</sup>

CBR thus aims to act as an alternative and sometime-corrective to research in which researchers articulate priority research questions for the community, collect data and develop analyses that they take back to their universities, and advance their own careers—often, in the name of “helping” marginalized communities, but without explicit benefits for the communities.

A new Federal Policy for the Protection of Human Subjects, passed in 2017, states that surveys, interviews, other forms of communication between researchers and human adults, and other low-risk projects can, beginning in 2018, be exempt from IRB review (though it is up to individual universities to implement

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<sup>7</sup> See Wallerstein and Duran (2003).

<sup>8</sup> For other discussions of tensions in activist scholarship, please see Charles R. Hale, *Engaging Contradictions: Theory, Politics, and Methods of Activist Scholarship* (University of California Press, 2008); Dána-Ain Davis and Christa Craven, *Feminist Ethnography: Thinking through Methodologies, Challenges, and Possibilities* (Rowman & Littlefield, 2016).

<sup>9</sup> See Hale (2008); Michelle Fine and María Elena Torre, "Intimate Details: Participatory Action Research in Prison," *Action Research* 4:3 (2006), pp. 253-69.; Sean Massey and Ricardo Barreras, "Introducing "Impact Validity"," *Journal of Social Issues* 69:4 (2013), pp. 615-32.

<sup>10</sup> Arjun Appadurai, "The Right to Research," *Globalisation, Societies and Education* 4:2 (2006), pp. 167-77.

<sup>11</sup> See Fine and Torre (2006).

the new rules).<sup>12</sup> These changes are helpful, but not sufficient. Many of the issues raised regarding accountability to and reciprocity with communities—such as those regarding ecologies of care, bottom-up accountability, and impact validity—remain relatively understudied and unaddressed.<sup>13</sup>

How can we ensure that research is capacity-building, and not just taking of community members' energy and resources? How do we operationalize ethical principles for productive collaborations?

*We forward these examples not as models to be copied and pasted (that would be against the spirit of community-driven research!), but as prompts for further conversation.*

One particularly exciting line of work has been that of formal Community IRBs (CIRBs, pronounced “cribs”), such as the Bronx Community Research Review Board in New York City, Special Service for Groups in Los Angeles, Hispanic Health Council in Hartford, and Papa Ola Lokani in Honolulu. Through such boards,

researchers receive feedback from community members, complete required forms and address questions they might not have considered otherwise, and design projects that address concerns that contribute to not just academic literatures but the communities they engage as well.<sup>14</sup>

Drawing upon a robust and growing literature, personal experiences and conversations and convenings, and existing work out there, we humbly present template/ example research ethics protocols for three scenarios in which formal CIRBs (like those aforementioned in the previous paragraph) do not exist. We forward these examples not as models to be copied and pasted (that would be against the spirit of community-driven research!), but as prompts for further conversation. Research protocols must take into each collaboration's specific

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<sup>12</sup> See the 2017 Federal Policy for the Protection of Human Subjects at <https://www.federalregister.gov/documents/2017/01/19/2017-01058/federal-policy-for-the-protection-of-human-subjects>, as well as discussion at <http://www.chronicle.com/article/Long-Sought-Research/239459>. In January 2018, the U.S. Department of Health and Human Services and 15 other federal departments and agencies announced a six-month delay in the implementation of this revised Common Rule, now scheduled for July 2018.

<sup>13</sup> Laura Pulido, "Frequently (Un)Asked Questions About Being a Scholar Activist," in *Engaging Contradictions: Theory, Politics, and Methods of Activist Scholarship*, (ed.) Charles R. Hale (Berkeley: University of California Press, 2008).

<sup>14</sup> Monique A Guishard, *Nepantla and Ubuntu Ethics Para Nosotros: Beyond Scrupulous Adherence toward Threshold Perspectives of Participatory/Collaborative Research Ethics* (City University of New York, 2015). Also see Community-Campus Partnerships for Health, "Community Irbs & Research Review Boards: Shaping the Future of Community-Engaged Research," (Bronx, NY: Albert Einstein College of Medicine, the Bronx Health Link, and Community-Campus Partnerships for Health, 2012); Phoebe Friesen et al., "Extending Ethical Strides: From Tribal Irbs to the Bronx Community Research Review Board," *The American Journal of Bioethics* 17:11 (2017), pp. W5-W8.

social/ political/ spatial contexts, and the positionalities of each participant and researcher in the collaboration.

## Working towards Ethical Community-based Research

The sample protocols below do not outline methods (like participant observation, survey, secondary data analysis, or semi-structured interviews), but they do reflect specific methodologies (here, critical, community-based theoretical approaches used to analyze and justify the theoretical models and specific methods chosen). We present them with the premise that we cannot ignore ethical tensions or wishfully hope that they do not come up—CBR collaborations are fraught with power inequalities, and talking about potential questions and tensions explicitly can help researchers to better address inevitable questions and engage in ecologies of mutual respect, care, reciprocity, accountability.

We hope that the sample protocols here will not be taken as universal formula or checklists. There are no best practices, but there remain some good practices for researchers to consider, tweak, and customize for each collaboration.

For instance, more community participation is not necessarily better in collaborative research. Asking community members to participate in every step of the research process might not be feasible or fair, and in a collaboration where different members have different resources and positionalities, “equal” divisions of labor are impossible, and certainly not equitable.

Through these sample protocols, we invite collaborators to consider:

- What do reciprocity and accountability look like, in this collaboration?
  - How are we being respectful of one another’s labor (including emotional labor), time, and priorities?
  - How do we treat seriously our roles as co-thinkers, intellectuals? How do we encourage critical inquiry by everyone, and work together when we don’t all agree on something?
  - How do we make sure that we respect each person’s voice in the collaboration, that no one is sidelined/ overlooked, and that we respect each person’s right to opacity/ privacy?
  - Ultimately, who benefits from this collaboration?

## A Hypothetical Scenario

Professor Blue would like to work with Green Power, an environmental justice group that primarily works with working-class African American and Latinx communities, in a CBR project. She approaches a Green Power staff member, Ms. Red, in the organization about the possibility of pursuing a project on how Green Power’s campaigns have responded to fracking and climate change deniers, and



how individual member leaders see themselves vis-à-vis other organizations in the larger environmental justice movement, especially those dominated by middle-class White leaders. Ms. Red expresses interest in the project, though she is much more interested in research that helps Green Power work with local politicians and win some new anti-fracking legislation than research on Green Power members' reflections on identities and the environmental justice movement.

Ms. Red is also a bit wary because a year ago, lots of community members spent time answering the same questions the foundations always ask them, and they never found out what happened with that past project. She wants to make sure that the same thing doesn't happen this time. She is also excited that because Professor Blue identifies as a woman of color, she might be sensitive about and relate to community perspectives in different ways than other researchers and foundation officers she's worked with.

Professor Blue and Ms. Red put aside time for at least two phone or in-person conversations about their potential research collaboration. During the first conversation, they outline their missions, and what research questions they were each interested in. They also discuss why they might be interested in such a collaboration. Through this conversation, they end up outlining a few principles and values they wanted to assert together. They also begin to figure out a feasible timeline for fieldwork for the project—They don't want to add to their workloads during stressful times, or right before looming deadlines, for instance. They also discuss other stakeholders in the project. Who else should they talk to, to flesh out details?

For the second conversation, Professor Blue visits the offices of Green Power to meet with both Ms. Red and at least one other staff member and non-staff community leader. Professor Blue presents what she understands to be the key research questions, proposed timeline, and general contours of the project. Together, they discuss whether the proposal so far makes sense, and flesh out some other expectations: How often would they meet? What sorts of methods might be appropriate? What sorts of products might they produce? In terms of organizing focus groups, for instance, who would call members to remind them of meeting times? Could Professor Blue pay for food and childcare during those focus groups? How often would Professor Blue present her hunches and findings? And could she help the Green Power leaders to present their research together, at conferences? Although Ms. Red mentions co-authorship of articles, the member leaders themselves say that they don't feel comfortable with academic jargon, and that they want to focus their energies on activities that have immediate impact in their community or on policymakers, not in academia. (Professor Blue is secretly a bit relieved, as her departmental chair told her that she needs more sole-authored articles, not co-authored ones, to get tenure. She is still thinking about different sorts of products to collaborate on, regardless.)

Professor Blue writes up some more details for her memorandum of understanding with Green Power, and she and Ms. Red sign it. Concurrently,



Professor Blue has been working on her university's IRB application, and finally gets approval. Research begins.

After a couple of months of fieldwork, Green Power also wants Professor Blue to help translate academic research into readable reports for both Green Power members and policy-makers. Professor Blue is happy to do so. Some tensions arise, however, when Ms. Red tries to push the organization to strike a deal with a local power plant, for a safety campaign on the polluting effects of its plants. While Ms. Red suggests that this deal would serve as an achievement for Green Power, Professor Blue, based on her research, wonders whether it would instead serve as a bad precedent, one suggesting that continued pollution and environmental racism would be tolerated as long as training programs were implemented. While getting the local power plant to do anything would be an achievement, the educational campaign would in some ways transfer the burden of safety from the power plant onto local residents, as if they could keep safe as long as they were informed—when no one should be exposed to these dangerous pollutants in the first place.

Meanwhile, the local newspaper picks up on Professor Blue's policy report, and gives her the chance to write an op-ed on Green Power's efforts. Professor Blue mentions the training program idea, but manages to contextualize it as one potentially helpful but small response among many, especially vis-à-vis a much larger need to address climate change and environmental racism now. She works with Ms. Red and a couple of the more active Green Power leaders on her op-ed draft. Once she submits the op-ed, however, the newspaper editors give her new edits and ask for revisions at what feels like (for an academic) an insane pace, usually asking for turnarounds in 12 hours. They want to publish this op-ed by Thursday! Professor Blue does the best she can, but she doesn't hear feedback on the revisions from Ms. Red and the member leaders in time for the deadline, and sends it in anyway. The op-ed gets published.

For the most part, folks are satisfied with the op-ed, and very happy about the publicity. As Professor Blue spends more time with Green Power, however, she also meets and talks with member leaders who disagree with Ms. Red on a number of issues—including the training program. Professor Blue is quite impressed with many of their points, ones that she hadn't thought of before, and which Ms. Red had never mentioned. She also begins to notice more disagreements and inequalities within the organization. (She can't tell whether the disagreements are partly due to power inequalities, cultural differences and misunderstandings, interpersonal clashes between individuals with strong personalities, substantive disagreements, or all of the above.) She wonders whom she's been inadvertently leaving out of her data, or whom she's become closer with and why, and how she can accurately document, analyze, and do justice to the complex dynamics at Green Power. She feels relieved, though, that she is not the only one with certain critiques of the organization's current campaigns, and that some member leaders have similar analyses.

Between Professor Blue's heavy teaching workload and her out-of-town trips to attend to her father's ill health, and the Green Power member leaders' own lives, the interviews are also going a bit slower than expected, and a couple of focus groups get canceled. Ms. Red is getting antsy, too, wondering why Professor Blue's analyses aren't done, and why Professor Blue isn't enthusiastically agreeing with everything she says, the way she did at the beginning.

### *Some considerations*

Although Professor Blue worked hard to anticipate ethical dilemmas, engage community members with reciprocity and accountability, and address issues of reflexivity, she was nonetheless caught off guard by tensions and events in her fieldwork. In retrospect, she especially wishes she had built in (and implemented) more moments of reflection and revision in her fieldwork, and thought through more opportunities for polyvocality, disagreement, and critical inquiry in her public work. She also wishes that she had sensitive discussions with members, folks besides Ms. Red, from the beginning. (On the other hand, she knows that the members might not have opened up for a while, until they knew that they could trust her, and she wasn't about to report their views to Ms. Red and others.)

- What other issues are likely to have arisen, besides those mentioned in the hypothetical scenario?
- What is the positionality of each member of the collaboration?
  - In considering our positionalities, we do not ask that each person divulge private or autobiographical details, though some may be relevant. Rather, we ask each person to consider how our backgrounds—in terms of work experiences and disciplinary training, social understandings, and racial, gender, sexuality, and other identities—inform how attuned we are to the policy and especially discursive debates surrounding the topic of our research collaboration. How do these backgrounds inform how we are perceived by others in the collaboration? For instance, in what ways might we as researchers be perceived as “insiders,” someone that community members can relate to, or someone who readily picks up on social signifiers outsiders might miss, and in what ways might we be perceived as “outsiders,” someone with a different educational background, or someone who can ask “naïve” questions that compel community members to articulate assumptions that insiders would have taken for granted?
  - What sorts of power, resources, bodies of knowledge (including embodied, local, and technical knowledge), and ways of knowing feel most familiar to each of us?
- What tensions in the hypothetical scenario can perhaps be addressed by developing and implementing a research protocol, like the ones below? What ethical tensions must be addressed in other ways?

## Scenario 1.

**Collaboration between a specific researcher/ research team and a community-based group/ organization.** In our first scenario, a researcher works with a community-based organization that has a clear structure (with staff, key community member leaders, maybe a board of advisors, and in some cases, an in-house researcher). In many cases, the CBO has had experiences with researchers before, and has some preferences on what good collaborations look like, based on those experiences. The following sample can serve as a *beginning* template for similar research protocols. Underlined language must be adjusted to fit the context; other text should be considered for revisions as well.

Memorandum of Understanding  
Between A. Blue and Green Power  
for the

Anti-Fracking Environmental Justice Project, January – September 2017

### Overall Framework

This Memorandum of Understanding (MOU) outlines some of the expectations for our collaborative research effort. Rather than a specific set of methods, we want this document to reflect an ethic of reciprocity and mutual respect and support, in which are mindful of limited time and resources, so that all collaborators can learn and benefit from this research project.

### Collaborators and missions

Green Power believes that social change to overcome systemic inequities begins with empowered residents fighting for environmental justice issues locally, as well as working in solidarity with climate change activists globally. Most relevant to this MOU, Green Power works with local residents who have campaigned against fracking locally and with larger environmental justice coalitions.

Anna Blue, of University of Color. Most relevant to this research project, (she has previously researched environmental justice issues, worked with these communities, etc.).

### Research Priorities

Green Power is interested in learning more about \_\_\_\_\_. *What was the experience like, in taking action to create positive change in their community? What does Green Power need to work with local politicians? What factors most shape the likelihood of new anti-fracking legislation?*

Anna Blue is motivated to work with Green Power because past activists, especially those from Latinx and African American and immigrant communities, have suggested that beyond questions of *Who participates?*, questions of racial equity—*Who benefits?*—remain unanswered. *Is Green Power promoting equity? What concerns do member leaders have—especially in terms of mobilizing power? How did the process of becoming Green Power leaders impact their understanding of environmental justice?*

### We Are All Producers of Knowledge

We are committed to participatory action research:

- to draw upon different types of expertise and knowledge in analyzing the conditions we live in and working towards social change,
- to co-creating research questions with members of the community (to make sure that the research speaks to community priorities),
- to working together in co-interpreting findings, whether on paper or in conversations, and making sure that different interpretations of the research are documented, and
- to engage in discussions regarding appropriate dissemination.

Together, we can work towards research that can be used to uplift, critique, and work to improve the participatory budgeting process, and our work with these democratic institutions. We attest to our commitment to the larger goals and missions of the collaborators, and also to each of our capacities as thinkers, with potentially different, respectful interpretations and conclusions from the research. We assume that distribution of mutually agreed upon research products will benefit all.

### Timeline

Green Power and Anna Blue will work to adjust research timelines to all collaborators' needs, as best we can. At this time, we expect to:

- Work on this project most during these months, when both Green Power and Anna Blue can devote some more time to this project.
- We work in iterations of data collection, analysis, and memo-writing.
- Anna Blue will provide mentoring, and provide options for potential co-authorship on different, possible resulting products (memos, reports, articles).

### Expectations

Green Power and Anna Blue, operating under this MOU, agree as follows:

*Re: fieldwork:*

- Green Power will convene member researchers and provide space for meetings at mutually agreed times.
- Anna Blue will plan research/ training activities, potentially including:
  - Learning what has been said about anti-fracking campaigns and environmental justice movements, what the current debates are
  - Documenting experiences in environmental justice in systematic ways
  - Constructing semi-structured interview protocols
  - Conducting interviews
  - Conducting analyses of outcomes and benefits
  - Writing policy memos, to present findings to city administrators/ policy-makers
- Anna Blue will oversee the research activities of the member research team, including:
  - Providing mentorship for co-facilitators
  - Debriefing and planning activities with co-facilitators
  - Communicating with staff about the research team's practices, developments, and needs
  - In collaboration with the co-facilitators, working to ensure that the members develop a meaningful research product or policy memo by this month, to present to policy-makers
- Anna Blue has secured Institutional Review Board ethics approval for this research, and thus all procedures associated with that approval will be followed by the research team, including obtaining informed consent and protecting confidentiality. Anna Blue will shepherd the

research through institutional ethics approval process, but we will proceed only if Green Power is in agreement with the procedures.

*Re: benefits:*

- Anna Blue will secure funds for compensation, such as gift certificates, and food (such as light snacks), for the member researchers' work.
- Anna Blue will work to secure speaking engagements or conference presentation opportunities in which the members can co-present research findings.

*Re: ownership of data, analysis, and writing:*

- Anna Blue will be responsible for the secure storage of any data collected.
- The data collected as part of the research conducted by Anna Blue and the member researchers belongs to the research team members, *collectively*. This means, in addition to the collective research products generated from the work, any research team member (including co-facilitators) can propose to create individual products from the data.
- Individual research products must be presented to the research team, including Anna Blue, and also to the Green Power staff and must include a product description, criteria for how authorship is determined, and a plan for how the product will be shared with the larger community. Research team members will have the opportunity to review any quotes/comments/facts/stories/data that comes from their lives before being made public.
- The Member Research team documents authored by Anna Blue as part of this MOU are hers to use and/or distribute. Green Power may also use and distribute the curriculum documents and will include Anna Blue's name.

Each party of this MOU is responsible for its own expenses related to this MOU. There will not be an exchange of funds between parties for tasks associated with this MOU.

### **Evaluation/ Check-ins**

At least twice during the research project (probably 1 and 2 months in), we will check in and evaluate our progress with this research project.

- Are there evolving research questions we need to ask, that community members want answered?
- How is the process of conducting this critical PAR project going?
- What adjustments should be made?

### **Terms of Understanding**

This MOU is for a period of one year from exact beginning date to exact ending date and may be extended upon mutual agreement. It shall be reviewed every 6 months to ensure that it is fulfilling its purpose and to make any necessary revisions.

### **Authorization**

This MOU is not a formal contract, but it implies that signatories will strive to reach, to the best of their respective abilities, the objectives stated here. By signing this MOU, we agree to its contents and to contribute to its further development.

Anna Blue  
University of Color

B. Red, Director  
Green Power

## Scenario 2.

**Collaboration between a specific researcher/ research team and a community without a formal organization, or a number of individuals within a community.** In our second scenario, a researcher works with a community group without a formal organization, or with a number of individuals within a community. In many cases, such groups or individuals have not had experiences with researchers before. The researcher must take on even more responsibility, then, to begin constructive discussions on what good collaborations look like. In such cases, the researcher might consider (at least) the following two options:

1. Constructing an *advisory board* of community members and perhaps some allies, who might work with the researcher to navigate ethical dilemmas, co-interpret findings, and think about questions of dissemination to maximize impact. This group could meet over a meal on a quarterly basis, for instance, or engage in workshops facilitated by the researcher in order to increase their capacities as co-researchers.
2. Writing an MOU or *Assent Form* to be signed by at least some of the community members the researcher works with, especially those that the researcher wishes to work with more closely. This MOU or Assent Form should go further than university-based IRB consent forms, and discuss expectations regarding ownership of data, analysis, and writing.

In these scenarios, questions of whom the researcher works the most closely with (and perhaps who end up with some representative power vis-à-vis the community at large) remain paramount. If possible, presentations of findings or analyses should engage community members beyond those the researcher works with most closely.

### Scenario 3.

**Collaboration between a specific researcher and a larger group of researchers working with the same community.** In our third and final scenario, a researcher is not the only one working with a specific community, on a broadly conceived research topic. For instance, especially if Green Power has been involved in some successful lawsuits or launched successful campaigns in the past few years, there may be researchers other than Professor Blue eager to work with Green Power. Although it may be impossible to establish and maintain contact with every researcher engaging a large institution/ process/ community, researchers should make every possible effort to do so, in order to coordinate resources and research projects, and to be respectful of community needs and mindful of the *cumulative impacts and dynamics* of various research projects.

Researchers should aim to involve not just all university-based researchers working with this community, but also community-based researchers and community members, in a *research board*. The following sample can serve as a *beginning* template for similar research board protocols. It is easiest to implement if one local researcher or organization serves as a Research Lead or Board Convener, helping to coordinate meetings. Underlined language must be adjusted to fit the context; other text should be considered for revisions as well.

Please see a sample Memorandum of Understanding for such a scenario on the next page.



## Memorandum of Understanding, Local Environmental Justice Research Board

The following Memorandum of Agreement outlines the roles and responsibilities of members of the local community concerned with environmental justice. The Research Board will help design and oversee research of local campaigns. As the Board Convener, \_\_\_ will plan and lead research meetings, as well as facilitate discussions of research instrument design, collection, and analysis.

### ROLES OF RESEARCH BOARD MEMBERS

1. Shape goals for research, prioritize research questions based on community needs, and provide feedback at critical stages of the research.
2. Advise one another about research process, instrument design and implementation, analysis and harmonization of research products.
3. Access raw data for analysis.
4. Create alternative research products (articles, reports, blog posts, etc.), with permission from the rest of the Research Board.
5. Support communications of research, including access to and preservation of past research.

### RESPONSIBILITIES OF RESEARCH BOARD MEMBERS

1. Participate in a total of \_\_\_ Research Board meetings or calls between date and date.
2. Assist with the development of research instruments.
3. Assist with data collection.
4. Provide resources and capacity for the research process, via student volunteers, access to space at academic institutions, funding or other resources connected to academic institutions, data analysis support, data entry, etc.
5. Research Board members may and are encouraged to elect to take on a concrete project within the larger research process. This information and analysis should be then made available to the rest of the Research Board. While the Research Board can advise on these concrete projects, we will not oversee or coordinate the work.

### TIME PERIOD

Research Board membership will last from beginning date to ending date.

### CONFIDENTIALITY

Since this research is community-based and is part of a larger project to aid local environmental justice campaigns, we want to be strategic about when and how we release and publicize data. Therefore, Research Board members will not share raw data or analysis in any form with anyone outside the Research Board without first getting prior approval.

### TERMINATION

Research Board members can terminate this agreement without cause, but must provide written notice. In addition, the Research Lead may terminate this agreement based on prolonged nonparticipation or lack of compliance with this Agreement.

I have read this Memorandum and do hereby agree to the above agreements.

Signature

Print Name

Date

\_\_\_\_\_  
Research Board Member

To be continued...

Without overextending the metaphor or conflating research ethics with interpersonal ethics, it may be helpful to think through what it means for a researcher to serve as a *critical friend* to the community. As friends, we engage in reciprocity, mutuality, respect, and accountability. We have a social contract that becomes endangered if one of us is abusive, or not acting in good faith. Still, it's impossible to articulate every aspect of our implicit contract as friends—a very exacting, meticulous, tit-for-tat sort of exchange of favors or gifts, for instance, probably feels transactional, calculating, and decidedly not friendly to most of us. Nor can we anticipate and adequately prepare for all moments of crisis; our negotiations and collective adventures mostly happen organically. Hopefully, we share a number of core values, but it's okay if we do not agree on everything. Critical friends have established enough rapport and trust to discuss matters in which we profoundly disagree, or if one of us feels that the other is pursuing efforts that are not in our long-term interest. Acting as critical friends requires us to call out/ call in others with care and respect, paying attention to how larger forces have shaped difficult decisions. For instance, in the hypothetical scenario, we can think about how Professor Blue might engage Ms. Red (and others at Green Power) as a critical friend. How might, or should, Professor Blue raise issues of governmentality, in which member leaders of Green Power shape campaigns as corporations and state agencies would like them?

*Without overextending the metaphor or conflating research ethics with interpersonal ethics, it may be helpful to think through what it means for a researcher to serve as a critical friend to the community.*

How might we work towards *generative conflicts*, disagreements that lead to constructive dialogues and help us to better understand the complexity of the situation at hand? Such generative conflicts demonstrate that we take each other seriously as thinkers, that no one is secretly patronizing the other and dismissing their opinions as uninformed or foolish. They allow us to grapple with contradictions and complexity in our work, and compel us to resist superficial consensus—especially when quite often, the appearance of consensus serves as a mask for domination.<sup>15</sup>

Such complexities also suggest that more participation is not always better. In addition to the sorts of research protocols sampled above, two other sorts of

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<sup>15</sup> Jo Freeman, "The Tyranny of Structurelessness," *Berkeley Journal of Sociology* (1972), pp. 151-64.

collaborative research products strike us as particularly helpful. The first, “who we are and why we write,” might serve as a brief manifesto, outlining individual and collective positionalities, as well as brief discussions of technical and local bodies of knowledge and expertise, and how these relate to the collaboration’s core values and findings. The second, a “statement on ethical misuse or misinterpretation of these findings,” compels us both to resist sociological flattenings (that people of any community or population tend to be this way or that, because survey results suggest, say, that a majority expresses this view) and essentialisms, whether positive or negative, and to collectively think through larger public debates and lines of discourse surrounding the communities or policies at hand.<sup>16</sup> How might we uplift the accomplishments of individual community members, say, without allowing such data to reify specious arguments regarding deservingness and minority exceptionalism? On the flip side, how might we include data on real-life struggles, or inequalities within our organizations and movements, without fueling deficit perspectives on community? Alongside fieldwork and analyses that foreground complexity, how might we engage in strategic positivism, at a moment when Congress has banned federal funding for even simple counting of deaths due to gun violence, and is considering banning funding for geographic mapping of residential segregation of housing inequalities?<sup>17</sup>

This document cannot come close to taking the place of courses on community-based methodologies. Rather, inspired by decolonizing, feminist, critical race, queer, and other critical theories, we write this as a working document for community members as well as those engaged in university-based conversation on critical methodologies. With this, we hope to prompt more sustained conversations to collectively imagine and articulate what alternative, community-based IRBs might look like—for research protocols that treat community members as participants and co-thinkers rather than subjects, that achieve “clarity through specificity” on good practices for reciprocity and accountability in CBR, and that contribute to meaningful democratization of knowledge production, a broadening of models of expertise, and greater ranges of modes of inquiry and dissemination.

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<sup>16</sup> Talia Sandwick et al., "Promise and Provocation: Humble Reflections on Critical Participatory Action Research for Social Policy," *Urban Education* 53:4 (2018), pp. 473-502.

<sup>17</sup> Elvin Wylie, "Strategic Positivism," *The Professional Geographer* 61:3 (2009), pp. 310-22.

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## Community Research Ethics in Red Hook

Maddy Fox<sup>1</sup>, Anna Ortega-Williams<sup>2</sup>, Catherine McBride<sup>3</sup>  
and the Red Hook Initiative

### Introduction

The Red Hook Initiative, located in the neighborhood of Red Hook, Brooklyn, has been experimenting with approaches to community-based research ethics for years. What follows is a brief outline of how we, a community-based organization and collaborating university-based researcher, have navigated research ethics in relation to outside research requests as well as our participatory action research collaborations.

The Red Hook Initiative (RHI) is non-profit organization serving the community of Red Hook in Brooklyn, New York. In partnership with community adults, RHI nurtures young people in Red Hook to be inspired, resilient, and healthy, and to envision themselves as co-creators of their lives, community and society.

The neighborhood of Red Hook, Brooklyn is a small, close-knit community that is geographically isolated from the rest of Brooklyn, cut off by water, highway, and tunnel. It is further isolated because the neighborhoods on the other side of the tunnel and highway are largely wealthy and majority white. Red Hook is home to one of the largest public housing projects in New York City. The Red Hook Houses officially house about 8,000 residents, though the actual number of residents is higher. If you search for “Red Hook, Brooklyn” in a scholarly database, you’ll find that there are dozens of published studies and various unpublished theses and dissertations that have focused on Red Hook. Scholars have studied

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innovations in approaches to justice in Red Hook, environmental impact post-Super Storm Sandy, urban development, Norwegian immigration, community resilience, urban agriculture projects, community oral history projects, and more. In addition to researchers, journalists and political officials often focus on Red Hook. And, the Red Hook Initiative collects a significant amount of internal data in response to their desire to learn and grow from self-study as well as, more recently, accountability pressures from funders. Even though some of the published work on Red Hook produces findings that have the potential to benefit community members, and some studies are participatory in their approach – the reality remains that this is data is extracted from the same people of Red Hook. Research fatigue and over-research are issues in Red Hook.

In light of the ways the research gaze is heavy on/in Red Hook and the frequent requests for the organization to serve as an ‘entry point’, RHI has developed strategies for negotiating research ethics and maintaining the power of local residents in relation to research.

## 1. Community-based Research Ethics Proposals

In 2015, the Red Hook Initiative pulled together a group of community leaders, advisors (including Maddy), and staff to think together about what it would take to launch a community-based ethics review board in the community. While there was significant interest for an independent ethics review board, it also became clear that the significant resources that would be needed to staff and support it were not currently available. The desire and potential for a community-based ethics review board still exists. However, in the meantime, RHI developed its own internal ethics review process.

RHI regularly receives requests from researchers, students, journalists, and politicians for access to young people, and/or community members, and/or community spaces. Anyone who contacts RHI with a research request is asked to respond to a set of questions and submit a proposal. In the proposal, researchers are not only asked to describe their research questions, methodologies, time-frame, etc. but, they must also describe how community members will be compensated, how/when the research will be shared with participants, and in what ways the research contributes to and may be harmful to the local community. The proposals are evaluated by RHI through a rubric that is accountable to the rights of

*The Research Ethics Proposals  
aim to prevent extractive research.*

community members. In the process of drafting proposals, researchers gain a sense of the kind of ethics and commitments expected of them in order to gain

access. The Research Ethics Proposals aim to prevent extractive research. Instead, most fundamentally, outside researchers who desire to research in Red Hook and/or with Red Hook residents via the RHI must demonstrate how their

research contributes to and supports the local community/community members and their visions for community change.

## 2. Participatory Action Research and Memorandums of Understanding

Red Hook Initiative's mission is rooted in the idea that local community members, including local young people, have the vision and expertise to enact the social change they desire. In line with those commitments, RHI engages with participatory action research (PAR) to investigate community issues and experiences, towards developing programs, interventions, and organizing/advocacy campaigns. RHI engages in community-based research (CBR) as an approach to engaging participants and local community members in organizing to create change. RHI's commitment to participation is central to RHI's model of community building, youth development, and community hiring. Participatory action research produces grounded knowledge that is actionable, it is capacity-building for participants and staff, it shapes institutional memory, and honors local expertise. PAR and CBR is consistent with RHI's commitments to being trauma-informed and building racial equity. In the context of Red Hook, a community where people stay connected for generations, it is especially significant that PAR projects leave a legacy of locally generated knowledge for present and future generations of neighbors, friends, family, and peers.

*Red Hook Initiative's mission is rooted in the idea that local community members, including local young people, have the vision and expertise to enact the social change they desire.*

Sometimes, PAR projects are conducted by RHI staff (including local community members), like when the Local Leaders program of RHI investigated experiences of mold for residents of public housing in Red Hook<sup>4</sup>. Other times, PAR projects are in collaboration with university-based researchers for instance, RHI collaborated with Aditi Mehta from MIT on a project about community-technological innovations post-disaster and with Maddy Fox, who has collaborated on PAR projects about education inequality, getting in and out of the neighborhood, and community perspectives on violence. The decision to engage in PAR projects is itself an ethical decision on the part of RHI.

And, for the PAR projects that involve university-based researchers, further ethical concerns need to be navigated. Maddy and RHI have now collaborated on three PAR projects. We've found that writing a Memorandum of Understanding, as described earlier, is important. But, we also know that a MOU is in reality a documentation of a set of commitments that need regular love and attention. Most

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<sup>4</sup> "The Impact of Mold on Red Hook NYCHA Tenants." (Red Hook Initiative, 2016)



important is that communication remains open and multi-directional throughout the research process and beyond. In our experience, elements spelled out in MOUs evolve in response to the desires of the PAR team. In our collaborations, RHI and Maddy might initially agree on a broad issue to explore, but the topic and research question always changes – and sometimes radically – once a community team is formed. For instance, in our most recent collaboration, Catherine and RHI invited Maddy to collaborate on a PAR project on young adult experiences and perspectives with violence in the neighborhood. Once the research team of ten young adults from the neighborhood came together, and we'd gone through a process of collectively honing our research questions, we all decided to use interviews as our methodology. Catherine and Maddy assumed that we'd ask young adults directly about their experiences with violence, but the local young

*Research isn't rigorous if the ethics aren't as well. The ethics of the research methods were shaped by the ethics of our commitments to each other and to our collective.*

adult members of the research team explained that to put interviewees (or each other) at risk for “snitching” was unethical. Research isn't rigorous if the ethics aren't as well. The ethics of the research methods were shaped by

the ethics of our commitments to each other and to our collective.

We assume most writing that emerges from our collaborations will be co-authored, and any solo-authored pieces go through the same review process as with any other researcher (as outlined above). All three of us, Maddy, Catherine, and Anna, are committed to relationships across community-university that are reciprocal and committed to exploring and negotiating power in relationship across institutions. In the process, and through these relationships, we enact a set of ethics that ultimately re-center power in relation to community-based knowledge-production and re-imagine what the academy can be (accountable to communities).