

Importance of a Place-based and Community-Moderated System of Research Oversight to Maximize Benefits for Social Change

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Research is a critical phase of the process of social change. The evidence generated by research is used to document inequities and disparities, frame debates, inform advocacy, mobilize change agents, and plan and evaluate the effectiveness of proposed solutions. Therefore, those who drive the research agenda drives the system of community social, economic, health, and educational improvements. Research investment from federal and local agencies, and private funders, is also a marker of a society's priorities in the way it invests in specific issues, geographies, and populations in the United States.

US System of Ethical Oversight of Research

The Institutional Review Board infrastructure in the United States was created to prevent the ethical violations that had historically occurred in research with human subjects. Now well-known unethical research like the Tuskegee Syphilis Study among African-American men and the Willowbrook hepatitis study among mentally disabled children revealed the predatory nature of clinical and experimental research, particularly research which generated commodifiable products such as pharmaceuticals (White, 2020). As a result, the US government enacted Federal Policy for the Protection of Human Subjects in 1974 (*Federal Policy for the Protection of Human Subjects*, 2017), and released the Belmont Report in 1976 ("The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research," 1979), which identified the ethical principles and guidelines that arose from past conduct of research. The

three basic ethical principles espoused by the Belmont Report respect for persons, beneficence (and avoiding maleficence), and justice (Miracle, 2016). Federal regulations and IRBs also emphasize the importance of additional consent and ethical protections of vulnerable populations such as children, prisoners, and pregnant women, as well as special classes of participants including students, employees, and cognitively impaired individuals who may be vulnerable in terms of coercion or ability to consent before participating in research.

In 1991, the US Department of Health and Human Services passed the Common Rule, which created a new system of research oversight meant to protect human subjects participating in federally-funded research (Rao, 2016). This oversight is facilitated by Institutional Review Boards (IRBs) accredited by the federal government to research institutions (e.g., higher education, hospitals), and consists of a board that reviews, approves, and oversees research protocols, including participant consent procedures. IRBs must consist of at least five members with different academic expertise, as well as one person not affiliated with the research institution to represent a community expertise. The Common Rule was updated in 2017 with input from all of the federal agencies that fund research, to modernize research oversight regulations. This “final rule” also established better guidance around participant consent, requiring that information about a research study has to be stated in language that a “reasonable person” would understand before they can be ethically expected to consent (*Revised Common Rule*, 2017).

One of the challenges of the existing infrastructure for research oversight is that the authority and capacity is placed in the hands of the research institutions. For research that occurs in communities, particularly vulnerable communities such as minority or impoverished

communities, this establishes a power dynamic where those conducting the research are beholden only to their own institutions and the federal government to determine the ethical conduct of their research. The communities themselves are essentially not a part of the process. For communities such as African-American communities, this lack of control over the research process combined with their history of being victimized by unethical research translates into long-standing mistrust of researchers and academia (Scharff et al., 2010; G. Corbie-Smith et al, 1999; Giselle Corbie-Smith, Thomas, and St George, 2002).

Failures of the US System of Ethical Oversight to Protect Communities

A long tradition in community-based participatory research (CBPR) in the field of public health argues that research that takes place in communities must equitably engage community partners in the design and conduct of research to ensure it generates knowledge that benefits the community and leads to social change (Israel et al., 1998; Minkler, 2000). CBPR approaches to research accomplish this by employing participatory strategies that break down these power dynamics between researchers and community members by sharing research roles and funding, building community research capacity, and valuing the knowledge, expertise, and contributions of all members of a partnership (Minkler and Salvatore, 2012; Carroll-Scott et al., 2012; Isler and Corbie-Smith, 2012). The benefits of a CBPR approach include its ability to promote equitable research partnerships between academic institutions and community-based organizations, improve the conduct and validity of community-located research, drive translation of research into interventions or policy, and achieve population-level outcomes such as sustaining community health improvements and achieving systemic change (Minkler, 2010; Santilli et al., 2011; Seifer, 2006; Jagosh et al., 2012; 2015; Santilli, Carroll-Scott, and Ickovics, 2016).

CBPR theorists and practitioners have identified areas where the existing IRB infrastructure is not set up to support research that engages with community change agents in roles beyond advisory or participant recruitment. Studies have found there is an insufficiently-funded burden of research on community-based organizations for research roles such as translation and recruitment for primary data collection, and that the community is not trained to contribute to the research and so do not feel their role is equitable (Tamariz et al., 2015; Otiniano et al, 2012; Amy Carroll-Scott et al., 2012). Further, IRBs have been found to lack an understanding of CBPR or other participatory models of research and do not have or require representation on its board of practitioners of CBPR (Tamariz et al., 2015). As a result, they are not equipped to suggest or require CBPR approaches to research that occurs within a community setting, particularly those most distrustful of research. The most common criticism of IRBs are their inability to represent diverse community perspectives given their requirement of only one community member to represent all of the many communities in which an institution conducts research (Tamariz et al., 2015). Although many IRBs include different types of non-institutional review board members, it is hard not to see this approach as an extension of tokenism (Niemann, Gutierrez y Muhs, and Gonzalez, 2020).

While IRBs are designed to ensure the protection of individual human subjects in the research process, they are not well-equipped to protect or respond to the broader interests of communities. For example, Federal regulations do not recognize vulnerable *communities* as deserving of additional ethical considerations such as prisoners or pregnant women. Yet the communities most likely to be researched are those that experience persistent socioeconomic

disadvantage, often as a result of economic exclusion and residential racial segregation, and so are indeed more vulnerable to research in terms of coercion or ability to consent.

Some argue the ethical principles of beneficence and nonmaleficence need to be examined by IRB review boards from the community's perspective instead of just for individuals (Mikesell, Bromley, and Khodyakov, 2013; Friesen et al., 2017). An additional ethical concern that arises in community-located research is *community autonomy* (Mikesell, Bromley, and Khodyakov, 2013). Communities require some level of autonomy to ensure that proposed research has respect for community needs, interests, values, strengths, dignity, worth, and that they are involved in the joint interpretation of findings and dissemination of results. Another ethical concern is *community justice* (Mikesell, Bromley, and Khodyakov, 2013). Research results can be stigmatizing to communities depicted as disadvantaged or "needy", which exacerbates internalization of stigma by community members (Jones, 2000). Community justice can also be violated when data collected from community members for one purpose can be used for another by the researcher without permission (Mikesell, Bromley, and Khodyakov, 2013).

Another challenge of the IRB system for community-located research that is not mentioned in the literature is that IRBs are not set up to assess or address geographic concentrations of research. This is due, in part, to the fact that individual IRBs oversee research conducted by their institution's own researchers. IRBs thus have no mandate to collaborate with other IRBs to determine if the research being conducted by its own researchers is duplicative of research being conducted in the same geography or population as research being conducted by other institutions. A further challenge is that IRBs do not routinely collect or code their research protocols by geographical focus, nor do they conduct routine assessments of the geographic overlap between

protocols. Therefore, there is no way to assess research burden on a particular community. As a result, there is no place-based, cross-institutional system for approving, overseeing, or communicating about research.

One solution for these ethical oversight failures is the creation of a community IRB, or community research review board (CRRB). While there is no system of supports or oversight of these solutions, there are several case studies in the US and reports that offer guidelines to communities attempting to create one in their locale (“Community Review Board Toolkit: A Guide to Plan and Conduct a Community Review Board,” 2013). Probably the most well-known is the Bronx Community Research Review Board (BxCRRB), a collaboration between an academic institution (Albert Einstein College of Medicine) and a community-based organization (Bronx Health Link) (del Campo et al., 2013). The BxCRRB was informed by focus groups of community residents about their perceptions of and attitudes toward research, and clear processes were co-established for applications, selection, and training of BxCRRB members. Researchers wishing to conduct research in the Bronx were initially recommended to come first to the BxCRRB to review and provide feedback on their proposed study and protocols, and then eventually the value of this process for improving the research and partnering early with community stakeholders spread word of mouth. One of their key lessons learned includes the challenges imposed by the costs and staffing required to organize and convene regular and frequent review board meetings, include online researcher submission processes. This has implications for how a CRRB process could be sustained by community members and community-based organizations already operating with limited budgets and research infrastructure.

West Philadelphia Promise Zone Context

The West Philadelphia Promise Zone is an urban area of roughly two square miles, including parts of 10 neighborhoods comprised of historically vibrant, predominantly African American communities. These neighborhoods include, or are adjacent to, large educational and health institutions such as Drexel University and the University of Pennsylvania and its hospital systems. Residents have largely not benefited from the economic growth of these “eds and meds,” experiencing a dramatically higher poverty (31.5%) and unemployment (11.7%) rate, and lower median household income (\$24,948), relative to other Philadelphia neighborhoods (United States Census Bureau/ American Fact Finder, 2017). Given that Philadelphia is the poorest of the largest cities in the US (Pew Charitable Trusts, 2018), this also means that West Philadelphians are living at levels of poverty far below national averages, and thus experience severe social and health inequities (Carroll-Scott et al., 2017). This is a reality likely to exacerbate as a result of the COVID-19 pandemic and its economic impacts.

West Philadelphia received its Promise Zone designation in 2014 from the US Department of Housing and Urban Development. Promise Zones were created in high-poverty communities where the federal government partners with local leaders to “increase economic activity, improve educational opportunities, leverage private investment, reduce violent crime, enhance public health and address other priorities identified by the community” (“Promise Zones - HUD Exchange” n.d.). Although the designation does not include grant funding, designees are assigned a federal liaison to help navigate federal programs, and preference points for certain competitive federal grant programs. In Philadelphia, community improvement activities are

driven by various Promise Zone committees (e.g., health & wellness, housing, education, safety and security, economic development) comprised of community leaders and local organizations, coordinated by the backbone agency, the Philadelphia Office of Community Empowerment and Opportunity, and staffed by AmeriCorps VISTAs.

Despite the Promise Zone initiative's mandate to facilitate community development and improvements in these neighborhoods, the guarantee of priority points on federal grants proposed to occur in the Promise Zone has increased already unsustainable levels of duplicative and disruptive research. Promise Zone residents have voiced concerns about research coercion, fatigue, the need for tangible benefits of research to their community, and a desire to partner in the research process to help formulate the research questions.

The Promise Zone Research Connection (PZRC), a community-led committee of the Promise Zone, began meeting in 2015 to discuss and address these community research concerns. The PZRC is currently developing its own CRRB that will be comprised of trained, human subjects trained and certified Promise Zone residents and independent researchers who will review research proposals that take place within the Promise Zone or target Promise Zone residents or stakeholders. The PZRC's mission is to create a strong, unified voice about how research can be conducted by: 1) advocating for the best interests of the community, 2) ensuring data and results are shared with the community, 3) establishing a line of communication for future community-researcher partnerships, and 4) advocating for a culture of community-engaged research principles and practices. Members believe the CRRB and its objectives are a necessary step to mitigate the negative culture of research that currently exists in the Promise Zone, and that this

change in research culture will increase the quality of research and its ability to drive positive community change.

Despite these successes, the PZRC has experienced challenges similar to the Bronx CRRB that point to systemic root causes. A recent survey of PZRC members revealed consensus around challenges facing the creation of a CRRB in the West Philadelphia Promise Zone: a lack of funding and staff to forward their goals. Despite a robust Finance Subcommittee seeking grant opportunities and submitting proposals, the only funding gained so far came from a small monetary award won by PZRC community leaders from a pitch competition at a local research institution as part of a commitment to CBPR.

The challenge is that local, federal, and foundation grant priorities are focused on specific outcomes depending on their field or issue of focus (e.g., asthma, community gardens, youth leadership development, job training). Very few even allow proposal submissions that fund infrastructure development in general, let alone infrastructure meant to increase community research capacity in general, and not tied to a specific focus or outcomes. Another barrier arises from the limited expertise of grant reviewers on this complex topic. The comments that come from grant reviewers engaged in *research*-focused funding mechanisms suggest they are not aware of the failures of the current IRB system to protect communities or of the detrimental effects of the power imbalance between communities and research institutions. Similarly challenging is that comments that come from grant reviewers engaged in *program*-focused funding mechanisms suggest they do not appreciate the role of a robust research infrastructure to drive effective interventions and outcomes. These are significant systemic challenges to the PZRC and other developing CRRBs.

Recommendations

This literature and the West Philadelphia Promise Zone experience suggest several recommendations to shift systems of power to ensure communities have the capacity and authority to govern research that occurs within their borders.

First, **local and federal public funders and private foundations should support the development and sustainability of place-based and community-moderated systems of research review and oversight**. Funders concerned with community development, empowerment, capacity, and improvements in various sectors (e.g., health, education, economic development) need to expand their funding priorities to include the development and sustainability of academic-community collaborations and community research review solutions. Such funding priorities would help to accomplish community-based organizations' missions and funders' desired outcomes in multiple focus areas with this upstream approach.

Second, **IRBs need to establish long-standing partnerships with community-based organizations as gatekeepers in the communities where their researchers conduct their research**. IRBs can do this by creating or expanding the role of a community liaison to develop and sustain partnerships with CRRBs and other community-based organizations in these local communities. IRBs can also increase the number and diversity of community IRB review board members to improve representation of various communities and community-based organizations local to the research institution and where a significant amount of its research occurs. Strong ties to nearby IRBs also improves the work of CRRBs, as it improves the pipeline between researchers proposing community-located studies with community gatekeepers.

Third, **IRBs should create processes to connect their researchers to established Community Research Review Boards.** The ideal mechanism to address the limitations of the current US system of ethical research oversight is for IRBs to collaborate with CRRBs for its community-located research, particularly research proposed to occur in vulnerable communities. IRBs should collect information about the geographic focus of research protocols and connect those researchers with the CRRB(s) that govern research in that community. As when multiple institutions collaborate on research, the research institution can either require a multiple-IRB protocol or allow the CRRB to be the single IRB of record.

Fourth, **IRBs need to increase their capacity related to community engagement and participatory research approaches.** IRBs could accomplish this by requiring the addition of review board members with CBPR expertise and requiring existing members complete participatory research trainings. Many such trainings exist, such as the Harvard Catalyst's Community-Engaged Research modules on the Collaborative Institutional Training Initiative (CITI) website (Calzo et al., 2016), or the Community-Campus Partnerships for Health's CBPR curriculum (The Examining Community-Institutional Partnerships for Prevention Research Group, 2006). IRBs can also require that investigators include community engagement and participatory research information in their research protocols: whether their proposed research is located in or recruits from local communities, zip codes where this will occur, proof of completion of participatory research trainings like those above, and a community engagement plan in their research protocol. These efforts would allow IRBs to understand when CBPR approaches would improve the beneficence or reduce the maleficence of research protocols

proposed to occur in vulnerable communities, and to make the necessary recommended revisions.

Fifth, **Community Research Review Boards need to be evaluated and shared to inform the development of new CRRBs and continuous quality improvement for existing CRRBs.**

For example, there have been other CRRBs and related efforts in West Philadelphia, including the University of Pennsylvania-led Philadelphia Area Research Community Coalition (Johnson et al. 2009) and the CRRB once established in the Kingsessing neighborhood of Southwest Philadelphia. However, all attempts by the PZRC to contact to collaborate or learn from these prior efforts in nearby neighborhoods indicate they are no longer functioning, nor are any lessons learned from their experience publicly available. Just as researchers learn from the successes and failures of past research, so do CRRBs need to build on prior efforts to focus their development and ensure their effectiveness.

In conclusion, community autonomy and community justice can be accomplished when the process of negotiating compromises between researchers and communities facilitates fairness and equitably distributes the burden and benefits of the research. Community-led, geographically-coordinated oversight of research would allow communities to work with researchers from across institutions to ensure that individual research proposals would benefit the community, avoid duplicative and burdensome research, and, most importantly, allow for the coordination of a place-based research agenda that facilitates knowledge generation to support community improvement and social change.

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