Community Engagement Practices of Philadelphia's Institutional Review Boards

Allison Rusgo, PA-C, MPH,[1,2] Amy Carroll-Scott, PhD, MPH[1]

[1]Drexel University, Dornsife School of Public Health, [2]Drexel University, College of Nursing & Health Professions

Background

Purpose: Explore Philadelphia's IRBs' practices related to community-engaged research (CEnR), in marginalized communities & how community-driven entities can strengthen relationships with research institutions.

Significance: West Philadelphia Promise Zone (PZ) is a 2sq mi area, including parts of 10 predominantly Black communities.

PZ neighborhoods are adjacent to research institutions, but residents experience significant economic & social inequities relative to other Philadelphians[1]



West Philadelphia received a PZ designation (2014-2024) to:

- Increase economic activity
- Improve education
- Reduce violent crime
- Address public health priorities[2]

It increased community-placed investigations—augmenting **research fatigue** & **desire for tangible benefits from studies**

In response, residents formed the Promise Zone Research Connection (PZRC) in 2016 & its Community Research Review Board (CRRB) in 2022 → **advocating for research that protects & benefits communities**

Methods

Approach & Design:

- Qualitative study; semi-structured interviews with senior IRB leadership (April-Sept 2021)
- Research team: Drexel University & PZRC community resident researchers
- Interviews conducted using a web-based platform with an average duration of 25min

Interview Question Focus:

- IRB practices concerning community engagement in study design & ethical review
- Geographic tracking
- Community IRB member engagement
- Feasibility of establishing a partnership with a community research review board

Analytic Process:

- Team coding via iterative consensus-building discussions
- Grounded theory approach to identify emergent themes & illustrative quotes
- Results shared with PZRC board members to co-create recommendations

Sample

All 17 IRBs in Philadelphia were recruited, 15 were interviewed

Table 1: Sample of Philadelphia IRBs

Type of organization	Number (%)
Academic institution	7 (41.2%)
Research hospital	4 (23.5%)
Nonprofit	2 (11.8%)
Department of Public Health	1 (5.9%)
School District of Philadelphia	1 (5.9%)
Did not respond or refused to participate	2 (11.8%)
Total Sample	**17**

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Thematic Results

1. IRBs' Focus

- Prioritize individual-level protections & lack community-focused safeguards—rely on researchers for community context

"The researcher is the expert…the IRB relies on the expertise of the researcher to provide us with all the information··· so that we can apply the regulatory requirements and···protect the participants and the communities they are a part of from undue risk." -IRB Director, Academic Institution

2. Training Requirements:

- Researchers & IRB staff complete CITI (or similar) training
- Researchers not required to complete CEnR training

Best practice: Require IRB staff to complete CEnR modules; enhances their ability to see how community voices are prioritized in a study

3. Geographic Tracking

- No mention of geographic systems to track institutions' research
- Barriers → old systems, lack of clarity on what/how to track
- Most agreed it would be helpful; some deemed it unnecessary

"We never consider geography in a medical context. In fact,…we'd…discourage considering geography because we want equitable access…to…treatments…Anyone should be able to come to [our institution]." -IRB Director, Academic Institution

4. Community IRB Member Inclusion

- All met federal guidelines
- Their expertise & perspectives are valued
- Challenges → inconsistent engagement, ill-defined job descriptions & compensation

Best practice: A community member consultant pool with broad expertise & knowledge

5. Feasibility of an IRB Partnership with a Community Research Review Board (CRRB)

- Lack of community-engagement interest among participants
- Some expressed a willingness driven by personal interests in CEnR & desire for new strategies (e.g., geographic tracking)
- Hesitancies included capacity limitations & institutional culture

"I think a lot of people have this attitude of like, 'Oh, well, I have to publish as many papers as possible…' and basically, I think the institution doesn't do a great job at basically connecting an individual's work with the work of the institution as a whole." -IRB Director, Academic Institution

Poster design by: *Claire M. Moore, Drexel University, Dornsife School of Public Health*

Recommendations

1. Require Community-placed Research to Articulate Community Benefits

- Researchers should describe how residents will benefit from studies
- Submissions should include community engagement & dissemination plans

2. Require Community-engaged Research Training

- Staff & review committee members should complete CEnR & Community-based Participatory Research (CBPR) education

3. Track Where an Intuition's Research is Conducted

- Submission forms should include a geographic focus
- Emphasize this enhancement to clinical institutions → patients reside in communities where systemic forces shaped their vulnerability to diseases

4. Increase Community Member Representation

- Engage with multiple community members (e.g., consultant pool)
- Create recruitment, retention, & compensation plans for community members & list them on their websites

5. Create an IRB Community of Practice

- Allows IRBs to share CEnR best practices & discuss strategies for engaging with communities overburdened by research
- Facilitates dialogue among IRBs about challenges & best practices unique to their field

References

1. 2017 American Community Survey Estimates, US Census. https://www.census.gov/data/developers/data-sets/acs-5year.html.

2. HUD Exchange (2024). Promise Zones Overview. https://www.hudexchange.info/programs/promise-zones/promise-zones-overview/.