

## Community Day at the IRB: De-Mystifying the IRB and Enhancing Community Understanding of Human Subjects Protection in Research - Or, What Happens behind the IRB Curtain?

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**Background:** The existence and activities of Institutional Review Boards (IRBs) are largely mysterious to the people in many communities. This problem is exacerbated by pervasive distrust among many people concerning Human Subjects Research (HSR). But, as potential participants are drawn from these same populations, it is hypothesized that when an IRB's activities are de-mystified, communities should feel confident that research participants are truly valued as stakeholders, partners, and persons.

**Method:** To foster this transformation, a "Community Day at the IRB" program was initiated at Johns Hopkins University (JHU) in Baltimore, Maryland, where members of the East Baltimore community and community advisory boards attended a half-day encounter with the JHU IRB. The program includes a meeting with the IRB's staff, an introduction to the IRB's operations, and attending of an IRB meeting. The session attendees then meet with the IRB's community representative for a question and answer period. Using a post-meeting survey, the attendees rated their experience, gauged the knowledge attained, and offered their comments and suggestions about how community engagement could be improved.

**Results:** Three sessions have been completed, with a total of 12 attendees completing the surveys. All participants had a favorable response to the event, with a consensus agreeing that community representation could be augmented.

**Conclusions:** This pilot project demonstrates that public understanding of research and research oversight is necessary to generate trust, while providing evidence that IRBs, researchers, and communities must operate from a position of shared trust and respect, so that research findings can benefit all communities.