Author's response to reviews

Title: IRB Challenges in Community-based Participatory Research on Human Exposure to Environmental Toxins: A Case Study

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Version: 2 Date: 18 May 2010

Author's response to reviews: see over
May 18, 2010

David Ozonoff, MD, M.P.H.
Editor-in-Chief
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Dear Dr. Ozonoff:

I am pleased to submit revisions to our manuscript originally entitled:  *IRB Challenges in Community-based Participatory Research on Human Exposure to Environmental Toxins: A Case Study* (ID 1897013089332896).

We are grateful to Robert Hood for his extremely thoughtful and careful review. The reviewer’s feedback helped us to refine our perspective, while also offering valuable information on what the federal regulations actually state.

We agree with the minor essential revision that asks us to clarify that our understanding of IRBs’ lack of familiarity with CBPR principles comes from our knowledge of a small number of IRBs dealing directly with CBPR researchers. We made this clear and wrote on page 28,

“We did not conduct a survey that would be representative of all IRBs, and hence our findings are not necessarily generalizable. However, we do think that the IRBs dealing with CBPR scholars would be more likely than other IRBs to have such familiarity, based on past applications by researchers to those IRBs. To better understand how IRBs in general deal with CBPR principles and the right-to-know that we emphasize, we recommend broad surveys of IRBs.”

We are pleased to see the reviewer’s attention to federal regulations on confidentiality applying only “when appropriate,” and have added that in two relevant parts of the article (the section “Who Gets to Know? CBPR and IRB Conflicts over the Dissemination of Information” and the section “What IRBs and funding institutions can do.”). Similarly, we were pleased to see attention to federal requirements that IRBs be competent to review CBPR or other approaches which reflect community attitudes; we have added that point. We have taken those two concerns and, following the reviewer’s advice, added a point about CBPR researchers and partners helping IRBs to understand the flexibility in regulation.

An overarching point made by the reviewer is that the above points may indicate that CBPR is not different in principle from IRB requirements. We have addressed this, with references to the AIDS and breast cancer examples he mentions, yet we still maintain that CBPR is a qualitatively different research approach.

We also followed the reviewer’s suggestion to add another recommendation in which we suggest that IRBs recruit not just any community members, but those who have experience with either CBPR or other...
community-engaged work. And we point to the benefits of such experience for many IRB reviews, not only CBPR ones.

We also add the point made by the reviewer that “The IRB should not consider possible long-range effects of applying knowledge gained in the research.” We discuss this in relation to a state agency review of research that had the potential to stimulate public advocacy for actions by that agency, creating a conflict of interest in the agency’s research review role.

We hope that these revisions address the reviewer’s excellent comments. If you have questions regarding our resubmission, please do not hesitate to contact me.

Sincerely,

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