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Community Engagement in Urban Health Research

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Engaging community members and organizations in the development and implementation of research has become an important aspect of biomedical, public health and intervention research.[1] In addition to respecting the interests and values of community members, collaboration with communities can provide unique perspectives and a wealth of information that can be incorporated into study design and implementation. This can consequently enhance recruitment and retention of participants and help produce valid and meaningful results.[2]

The practice of involving communities in research has developed over recent years both in response to a perceived mistrust between communities and researchers and in an effort to enhance research by improving the quality, relevance, and impact of research in the community.[3,4] This mistrust has been generated by valid community concerns that perhaps well-intentioned research investigators have "used" communities as laboratories without engaging the community in defining priorities, planning studies, or developing implementation strategies.[5] Community members have also voiced concerns that researchers may actually be more vested in personal and professional gain than in benefiting the communities they study or the larger society.[6,7] Principles have been developed to aid researchers to consider Community-based Participatory Research as a potential solution to these problems.[8]

In this issue of the Journal, Flicker, et al, describe the principles of Community-based Participatory Research and argue that "this approach has evolved as an effective new research paradigm that attempts to make research a more inclusive and democratic process by fostering the development of partnerships between communities and academics to address community-relevant research priorities."[9] They report a 2004 content analysis of 30 US Institutional Review Board and Canadian Research Ethics Board review forms and materials from major research institutions and conclude, not surprisingly, that community engagement is rarely taken into account in research review.

The authors also offer some interesting recommendations for review boards to use in assessing the adequacy of involvement of communities in research planning and implementation. They argue that research review boards that evaluate public health and population-based research should move away from the biomedical model that primarily focuses on assessing risks to individuals and assuring the informed consent of participants toward assessing risks to communities and creating methods for community consent.

A review of the current practice in community engagement in urban health research reveals a broad range of approaches applied in various types of research

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studies.[10] However, there is lack of consensus as to which method of involving communities is appropriate for each type of research. This is particularly the case in large epidemiologic and observational studies that do not include an intervention component.[11] Although Community-based Participatory Research is clearly helpful and appropriate in some research settings and with some types of research strategies, there remains a set of unanswered questions about this innovative approach to urban health research. These questions range from the optimal method to define a community of interest and its representatives,[12] to empirical questions about measuring the actual benefits and risks to communities and to research studies of engaging communities.[13] There are also concerns about whether all urban health research requires the extensive involvement of communities as defined by the principles of participatory research. Much of urban health research involves epidemiologic and observational studies that one might argue requires respecting communities of interest but could be justified without engaging communities as full partners in research design or warranting the right of community consent or refusal.

Community involvement can occur along a spectrum from lesser to greater engagement consistent with the type and complexity of the research project. Community consultation or review of proposed research projects can be accomplished informally or by more formal methods such as the creation of a community advisory board. Some have argued that community consultation should only identify possible risks and concerns, not a formal process to approve or disapprove individual research projects.[14] A recent National Research Council/Institute of Medicine report concludes that no single model of community involvement will work in all situations and in all types of research, and often community consensus need not be a precondition to conduct research.[13] However, the report encourages researchers to assess and address all community concerns before initiating a community-based study of any type and to report these interactions to the institutional review board as part of the review process. Finally, the report raises a practical concern about research funders providing adequate support in time and money to allow for serious partnerships to develop between research institutions and investigators and their communities.

At this point in time, institutional review boards ought not to be expected to have developed robust procedures for the review of community engagement in urban health research. There has been little guidance from governmental regulators and little dialogue among leaders in the research ethics field about this important subject. Review boards appropriately continue to focus on the risks of research to individual participants as new models for assessing the role of communities in research are developed.

Meaningful community engagement in urban health research is an aspirational goal that deserves the attention of the research community and the public at large. As we experiment with varying approaches to this new research model, we should be sure to collect empirical data on the risks, benefits, and outcomes of community involvement as partners in research to develop the best strategies to implement the principles of community-based participatory research. As we develop more knowledge and experience, institutional review boards will be better able to create review strategies that assess the adequacy and appropriateness of community engagement, and federal agencies responsible for research review will be able to provide guidance on the principles and practices that ought to govern involving communities as partners in the research enterprise.

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