

Better ethics education needed in community-based research

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A growing number of health research programs are collaborating with community groups to conduct research. The groups help recruit study participants, obtain informed consent, collect data and provide input on study design and procedures.

But existing programs that educate researchers, community groups and institutional review boards about research ethics "fail to meet the needs of all groups that have a role in community-engaged research," according to an article in the *Journal of Empirical Research on Human Research Ethics*.

First author of the study is Emily E. Anderson, PhD, MPH, an assistant professor in the Neiswanger Institute for Bioethics & Health Policy of Loyola University Chicago Stritch School of Medicine.

Community-engaged research has been defined as research that provides communities with a voice and role in the research process, beyond simply providing access to research participants.

Community-engaged research raises numerous unique ethical issues that have not been fully explored from the perspectives of all parties, Anderson and colleagues write. Academic and community partners sometimes have different goals, expectations, access to resources, work styles, types of expertise or interpretations of research results. Community-engaged research also may pose risks to all members of a group -- even those who do not participate directly in the research --

when findings potentially could label or stigmatize the entire group. Community partners also may experience distress when conducting research in communities where they work or live, due to feelings of responsibility beyond their research roles.

To address these and other ethical issues, the authors recommend numerous best practices for members of institutional review boards and those involved in community-engaged research partnerships. The authors also proposed a detailed research agenda for studying ethical issues in community-engaged research from the perspective of several stakeholders.

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Anderson, who is corresponding author of the article, has worked with several community-engaged research projects in Chicago. Her research interests include empirical research in [bioethics](#), institutional review board policy and processes, health disparities and [ethical issues](#) in public health research and practice. She also has served on several institutional review boards.

Provided by Loyola University Health System

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