Understanding Community-Based Processes for Research Ethics Review: A National Study

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Community-engaged research (CEnR) is increasingly recognized by national health organizations, funding agencies, researchers, and community groups as critical to addressing our nation's pressing health concerns.[1–7] CEnR's emphasis on community engagement raises ethical considerations that go beyond individual-level protections to include those at the community level. This focus on communities creates challenges for the institutional review board (IRB) system in the United States. IRBs, designed to protect the rights and welfare of individual study participants, may be less equipped to protect the rights and welfare of communities involved in research. The Belmont principles[8] that guide IRBs do not explicitly address the scope of ethical considerations that arise in CEnR; thus, IRB application of these principles may not provide a thorough ethical analysis.[9–11]

For example, in a review of 30 application forms from university-based IRBs, Flicker et al. found that community considerations were often missing.[10] Although all forms inquired about scientific rationale, none asked about the involved community's input regarding study justification. Only 4 forms asked about community- or society-level risks and benefits, and only 5 asked how findings would be disseminated. Additionally, Deeds et al. analyzed IRB feedback on a multisite community-based HIV prevention proposal and found that only 17% of the IRB comments focused on direct or indirect community issues.[12] Studies of CEnR researcher experiences with IRBs reveal deep concerns about the need to expand the ethical analysis to include community-level considerations of social justice, risks, and benefits.[13–20] Some researchers have questioned whether community-based review processes are better situated to understand actual risks and benefits, as compared with institution-based IRBs.[21]

A growing number of community groups have implemented ethics review processes to determine how (and whether) research is conducted in their communities. These processes operate independently, parallel to or in partnership with institution-based IRBs, and in some cases they are structured as community IRBs.[22–28] With the exception of federally recognized community IRBs, community-based review processes are not mandated or regulated, and little is known about them beyond reports on individual experiences.[25–27]

To gain insight into how ethics review of CEnR can be enhanced, we sought to systematically describe community-based processes for ethics review of research in the United States. Such understanding is essential given the increasingly frequent occurrence of CEnR and the growing body of literature indicating that institution-based IRBs cannot always provide a thorough and relevant ethical assessment of such research.

Objectives. Institutional review boards (IRBs), designed to protect individual study participants, do not routinely assess community consent, risks, and benefits. Community groups are establishing ethics review processes to determine whether and how research is conducted in their communities. To strengthen the ethics review of community-engaged research, we sought to identify and describe these processes.

Methods. In 2008 we conducted an online survey of US-based community groups and community–institutional partnerships involved in human-participants research. We identified 109 respondents who met participation criteria and had ethics review processes in place.

Results. The respondents' processes mainly functioned through community–institutional partnerships, community-based organizations, community health centers, and tribal organizations. These processes had been created primarily to ensure that the involved communities were engaged in and directly benefited from research and were protected from research harms. The primary process benefits included giving communities a voice in determining which studies were conducted and ensuring that studies were relevant and feasible, and that they built community capacity. The primary process challenges were the time and resources needed to support the process.

Conclusions. Community-based processes for ethics review consider community-level ethical issues that institution-based IRBs often do not. (*Am J Public Health.* 2011;101:S359–S364. doi:10.2105/AJPH.2010.194340)

METHODS

During the summer of 2008, we conducted an online survey of community groups and community–institutional partnerships that were involved in human participant research. The involvement of these groups and partnerships consisted of either directly conducting such research or advising on its conduct. We developed the survey with the guidance of a Study Advisory Committee comprising experts in IRBs, CEnR, and the operations of community-based organizations. Survey questions addressed the following topics: description of community group or partnership, types of research reviewed, review process infrastructure, review process functioning, review process benefits and challenges, and relationship of the review process to an institution-based IRB. Most questions were multiple

choice; there were also several open-ended questions. We worked with representatives of community groups and community–institutional partnerships to pilot test and revise the survey for clarity, completeness, and ease of use of online administration.

Only US-based community groups and community–institutional partnerships involved in human participants research were eligible to complete the survey. We found no existing database from which to draw the survey sample, so we constructed the sample by using a standard set of search terms to systematically search online grant databases, bibliographic databases, and conference programs. We also sought additional prospects by querying list-servs, study advisory committee members, and the national organizations of community groups that wrote letters of support for the study.

As a result of these efforts, we identified and e-mailed a study invitation to 1055 community groups and community–institutional partnerships presumed to be involved in human-participants research. Twenty-seven e-mails were returned as undeliverable, so we removed those prospects from the sample, resulting in a sample of 1028. Invitees were classified as nonrespondents if they did not complete the survey after 3 e-mail reminders.

Two hundred invitees completed the survey. We contacted a random sample of 100 non-respondents by telephone up to 3 times to determine whether they had received the e-mail invitation. Fifty of the nonrespondents did not respond to the phone calls. Of the 50 nonrespondents reached by phone, 38 indicated they had not received any of the e-mails about the study. Consequently, we estimated that 38% of the sample (n=391) did not receive the study invitation, resulting in an estimated effective survey sample of 637 (1028 − 391). Therefore, the estimated response rate was 200/637, or 31%.[29]

Of the 200 survey respondents, we excluded 28 from the analysis because they did not meet study inclusion criteria of being based in the United States and of being involved in human-participants research.

We performed descriptive statistical analyses using SAS version 9.1 (SAS Institute, Cary, NC), and we performed thematic content analysis on responses to open-ended questions.

Thematic content analysis consisted of 2 research team members independently conducting line-by-line coding of responses to build a codebook. We refined the codebooks through comparison, categorization, and discussion of the interpretations of the codes[30] until they achieved an intercoder reliability rate of 0.90.[31]

RESULTS

Of the 172 survey respondents that met the study eligibility criteria, 109 (63%) indicated that their group or partnership had a review process to determine whether to support, participate in, or conduct research; 30 (17%) indicated they were planning to establish a process; and 33 (19%) reported no plans to establish a review process. We report findings for the 109 respondents that currently had a process in place.

The review processes of the 109 respondents operated in 31 states, the District of Columbia, and Puerto Rico, including 6 that served multiple states and 6 that were national. Most respondents identified themselves as community–institutional partnerships (n=34; 31%), followed by community-based organizations (n=24; 22%), nonprofit organizations (n=13; 12%), community health centers (n=13; 12%), and tribal organizations (n=8; 7%). The remaining respondents (n=17; 16%) represented various other entities, including K–12 schools and community coalitions.

When asked what kinds of proposals they reviewed, 87% of the respondents (n=95) reported reviewing community-based participatory research proposals, with health disparities research representing the most frequently occurring substantive focus of proposals reviewed (n=69; 63%). More than 85% of the respondents indicated that they reviewed federally funded research. Table 1 summarizes the types of research reviewed. Seventy-one of the respondents (65%) indicated that they reviewed 2 to 10 research proposals annually.

Establishment of the Review Process

More than one quarter of the respondents (n=32; 29%) established their review process after 2005, and more than half (n=67; 61%) had done so since 2000. Forty respondents (37%) reported that their group/organization

TABLE 1—Characteristics of Research Reviewed: Groups Conducting Community-Based Research Ethics Review Processes (n = 109), United States, 2008

Type or Focus of Research	No. (%)
Approach	
Community-based participatory research	95 (87)
Social and behavioral research	60 (55)
Health services research	52 (48)
Clinical research	39 (36)
Quality improvement	36 (33)
Substantive focus	
Health disparities	69 (63)
Diabetes	47 (42)
Cancer	45 (41)
Obesity	42 (39)
HIV, mental health	35 (32)
Population focus	
Adults	91 (83)
People of color, women	76 (70)
Men	62 (57)
Adolescents, seniors	56 (51)
Children	54 (50)
Racial/ethnic group focus	
African American, Latino	44 (40)
Mixed	33 (30)
No particular racial/ethnic group	26 (24)
American Indian, White	23 (21)
Pacific Islander	15 (14)
Geographic focus	
Urban	67 (61)
Rural	38 (35)
Suburban	26 (24)
Tribal	15 (14)
No particular areas	14 (13)
Federal funding sources supporting submitted research[a]	
National Institutes of Health	58 (62)
Centers for Disease Control and Prevention	41 (44)
Health Resources and Services Administration	28 (30)
Indian Health Service	12 (13)
Environmental Protection Agency	8 (9)

Note. Respondents were allowed to indicate all that applied.
[a]Ninety-four respondents (86%) reported reviewing research funded by federal sources of support.

had secured a Federalwide Assurance from the federal Office of Human Research Protections. Table 2 lists the reasons we presented to respondents as options for why they had established a research ethics review process. Respondents were allowed to select all applicable reasons.

"Other" reasons cited for developing a review process included, for example, "assist in establishing equity in the decision-making process," "ensure research efforts are culturally appropriate," and "ensure that research is consistent with our institutional mission . . . [and] that leadership and resources are available to effectively support proposed research."

Review Criteria and Decision Making

The survey presented this open-ended question: "Briefly describe your group/partnership's process for making decisions about whether to support, participate in, or conduct research." Responses revealed 2 major themes: (1) criteria for making decisions to support, participate in, or conduct research; and (2) processes used for making decisions. Responses describing decision-making criteria emphasized the importance of engaging community members in the decision-making process throughout the review and the research itself, the relevancy of the proposed research; tangible benefits for the community (such as increases in knowledge, resources, community capacity, or access to resources), and the feasibility of conducting and completing proposed research, considering the expertise, skills, resources, and time needed. Some responses elaborated on voting procedures and final decisions that required the approval of a specific board, commission, or individual director.

Respondents also indicated the importance of 13 considerations when reviewing research proposals, rating each as not important, somewhat important, or very important to the review outcome. Table 3 presents the percentages of those agreeing that a specific consideration was "very important."

Fifty-eight (53%) respondents reported that the sponsoring group/partnership's executive director served as a reviewer. Reviewers also included community members (n=52; 48%), academic faculty or staff (n=46; 42%), employees of community-based organizations

(n=44; 40%), and employees of state or local health departments (n=22; 20%). Forty-three (39%) also indicated "other" reviewers, which included board members, tribal councils, and agency partners. Additionally, several respondents indicated that reviewer composition depended upon the type of proposal being reviewed. Types of training provided for the reviewers were no training provided (n=32; 29%), observation of the review process (n=22; 20%), participation in a nonspecified training developed by the group/partnership (n=39; 36%), and completion of an online training program (n=28; 26%). Respondents were allowed to choose multiple responses.

Concerns Identified During the Review Process

In responses to an open-ended question about concerns identified through the review process, the primary themes that emerged were: risks, benefits, feasibility, community or organization engagement, and relevance. Most of the responses that addressed risks focused on individual-level considerations (e.g., "inadequate safeguards for participants") rather than community-level considerations (e.g., "not enough protection for communities built into the proposals"). Most of the responses concerning benefits focused on community-level benefits (e.g., "how will this benefit our specific

TABLE 2—Possible Reasons for Establishing a Community-Based Research Ethics Review Process: Groups Conducting Community-Based Research Ethics Review Processes (n = 109), United States, 2008

Reasons	No. (%)
To make sure the community directly benefits	93 (85)
To make sure the community is engaged	82 (75)
To protect our community from possible risks	74 (68)
To respond to a growing number of researchers asking us to support or participate in their research	45 (41)
To set our own research agenda	18 (17)
Other	23 (21)

Note. Respondents were allowed to indicate all that applied.

TABLE 3—Factors Considered "Very Important" When Reviewing Research Proposals: Groups Conducting Community-Based Research Ethics Review Processes (n = 109), United States, 2008

Factors Considered "Very Important"	No. (%)
Research methods are appropriate to the community	104 (95)
Culturally appropriate recruitment strategies	98 (90)
Plans to share findings with communities involved in research	96 (88)
Culturally appropriate individual informed consent	96 (88)
Good fit with community's agenda	95 (87)
Community-level risks and benefits	94 (86)
Community consent	94 (86)
Shared power and resources among partners involved in the research	85 (78)
Plans to translate research findings into practice or policy changes	85 (78)
Opportunities for community training or capacity building	82 (75)
Community involvement in all phases of the research	76 (70)
Signed partnership agreement or memorandum of understanding	71 (65)
Plans to share findings beyond involved community	60 (55)

Note. Respondents were allowed to indicate all that applied.

community, as opposed to the general good of society") rather than individual-level benefits. Feasibility responses focused primarily on adequacy of funding and other resources (e.g., time, staff), and some of these expressed concern about impacts on service delivery. More than 70% of the responses pertaining to concerns about engagement focused on appropriate community engagement, with many of the remaining responses touching upon appropriate organization involvement. Concerns pertaining to relevance were split between relevance to community and relevance to the participating organization (i.e., to the organization's mission). Concerns less frequently mentioned included cultural considerations, dissemination plans, power sharing, research design, and data ownership.

Review Process Benefits

In responses to an open-ended question regarding the benefits of having a review process, the primary themes were: (1) to ensure that research is relevant or beneficial to the involved community or organization, (2) to engender a stronger community voice in determining which studies to approve, and (3) to create opportunities for capacity building. Examples of benefits reviewers looked for included projects that would "improve health outcomes," "reduce health disparities," and "contribute to policymaking decisions." In an example of a statement coded as capacity-building, a respondent stated how the review process "exposes community members to the research process and enterprise to help develop their expertise and knowledge about health issues and disparities in health." Numerous respondents said the benefits of the review process were obtained only when there was equality among reviewers and a commitment to listen to different voices.

The impact of these benefits was seen as contributing to "greater community support and trust" as well as improved quality of research; or, as a respondent stated, the process "helps us to focus on research being done the right way, rather than getting steered into projects that seem like a lot of resources but ultimately end up hurting the community due to improper research methodology." In essence, a perceived benefit of the review process is how it allows for a framework to determine

systematically which studies to approve based upon the criteria that are important to the involved communities or organizations.

Review Process Challenges

Multiple themes emerged in response to an open-ended question regarding review process challenges: time, recruitment and support of engaged reviewers, coordination with external entities, and infrastructure to support the review process. The subthemes related to time included: (1) time required to coordinate one's review process with other entities, such as different community groups or other ethics review processes; (2) time required of volunteer reviewers to prepare for and attend the review meetings; (3) staff time required to coordinate the process, which often is an added responsibility to their already busy schedules; and (4) time required to discuss and review protocols, especially when competing agendas or diverse perspectives exist among reviewers.

Responses addressing difficulties in recruiting and supporting informed and engaged reviewers focused primarily on the challenges associated with reducing barriers to participation and ensuring that all reviewers received adequate support to conduct informed assessments (i.e., training, access to comprehensible review materials). Challenges with external entities (i.e., institution-based IRBs, academic-based researchers, research sponsors) focused upon differences in underlying priorities or values. For example, a respondent cited "conflict with other IRBs that do not address group harm." Another wrote, "Some [researchers] are stuck in the old ways of doing research where they pay a few people and claim that they have community involvement." Responses citing the challenge of having sufficient resources to support the review process discussed problems associated with inadequate infrastructure to support staff and provide training.

DISCUSSION

When we began this study, little was known about community-based processes for research ethics review beyond anecdotal reports. We found new knowledge about where these processes were geographically located and physically housed, why they were established, how

they functioned, and the ethical issues that arose in their review of research. Our findings point to future growth in the establishment of these processes. More than half of these processes (62% of 109) had been formed since 2000, and 30 processes were currently under development.

Most of the community groups and partnerships that had established processes for research ethics review appear to have done so to influence how research was conducted in their communities and to serve in a protective role, with a minority intending to set the agenda for research in their communities. These processes, housed outside of academic institutions and operating in most states, have routinely considered community-level ethical issues that institution-based IRBs do not.[10] Flicker et al.'s content analysis of 30 university-based IRB application forms, for example, found that none of the forms asked about the following issues, which our survey respondents identified as important review considerations: community consent for the study, shared power and resources among partners involved in the research, and community training or capacity building as part of the research. Perhaps not surprisingly, community-based research ethics review processes were more concerned about disseminating findings to the communities involved in the research than to those beyond it. They had broader participation from individuals in non-academic settings than institution-based IRBs tend to have.[32]

Our study findings raise critical questions about the ethics review of CEnR. Should the scope of IRB review be explicitly expanded to include community-level ethical considerations? The national advisory committee that provides expert advice and recommendations to the Secretary of Health and Human Services on the protection of human research participants has begun to consider this question.[33] The Belmont principles that guide IRB review do not preclude IRBs from reviewing community-level ethical issues,[9] and the recently revised voluntary IRB accreditation criteria include a new standard stating that the accredited organization "promotes the involvement of community members, when appropriate, in the design and implementation of research and the dissemination of results."[34] IRBs would need to increase their understanding of CEnR,

strengthen their community composition,[35,36] and explicitly include community-level ethical considerations (e.g., those reported in Table 3) in their policies, processes, and application forms.[10] A forthcoming curriculum is designed to support IRB actions in these areas.[37]

Additionally, should CEnR proposals being reviewed by institution-based IRBs also be reviewed by a community-based review process? Although we anticipate that institution-based IRBs will, over time, respond in the ways we have suggested here, the protection of communities may be more appropriately situated in review processes developed and managed by the communities involved in research. A system involving community-based and institution-based research ethics review may be the ideal to strive for, despite the inevitable challenges and complexities involved.[38,39] Case studies of community-based review processes, including those that involve institution-based IRBs, would help to clarify how such a system might be established and supported. One question to be resolved is whether all research conducted in communities should undergo community-based review, or whether community-based review should be limited to research that meets certain conditions.

Unfortunately, many communities—particularly those most affected by the social injustices and inequities that CEnR seeks to address—do not have the resources to create and sustain research ethics review processes.[40] Institutions, as the main recipients of federal research grants, are able to support their research ethics review systems in part through indirect rates charged on those grants. Although federal funding agencies have begun to acknowledge the need to build research infrastructure in communities,[41,42] these efforts are not sufficient, and they privilege institutions as the funded entity.

Our study has several limitations. The sample did not include all community groups and community–institutional partnerships in the United States involved in human-participants research, because no comprehensive registry of these entities exists. Our response rate, though comparable to those of other online surveys,[43] limits our ability to generalize our findings. Our survey only asked explicitly about community-level ethical considerations, so our findings do not allow us to compare community-based processes for research ethics review and

institution-based IRBs with respect to individual-level ethical considerations. We are also unable to shed light on the relative impact that different review considerations can have on a decision of whether to support a given study. Because we did not ask respondents how they defined "community," we are also unable to examine how this definition may relate to how their review process functions. Nevertheless, by identifying and describing 109 community-based processes for research ethics review, we have shed light on critical mechanisms for community ownership of and control over research.

Our study is particularly timely because it coincides with increasing federal investments that will only bring the ethical challenges of CEnR further to the fore.[44–47] The Clinical and Translational Science Award Program, for example, is reengineering the way research is conducted in academic medical centers across the country, with community engagement and CEnR as central features.[48] The community and academic partners participating in these and other networks are seeking innovative solutions to the ethics review challenges posed by CEnR.[49,50] Indeed, our survey respondents expressed significant interest in contributing to the field's development, with 55% (n=60) indicating a desire to participate in a collaborative research network. Subsequent phases of our study will involve further analysis of our survey data and in-depth case studies of selected survey respondents' review processes and outcomes. ■

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Contributors

N. Shore, K.A. Wong, L. Moy, A. Corage Baden, K. Cyr, and S.D. Seifer collaborated in conceptualizing and implementing the study. N. Shore, R. Brazauskas, E.

Drew, J. Ulevicus, and S.D. Seifer collaborated in analyzing and interpreting the data. All authors participated in writing and revising the article.

Human Participant Protection

The institutional review boards at the University of Washington and the University of New England determined that our study protocol did not require a review.

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