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Community–University Partnerships in Community-Based Research

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Abstract

Problem—Community-engaged research (CEnR) is a complex, collaborative process that presents many challenges and requires investment of time and commitment by both community and university research partners.

Purpose—This paper describes the experience of a group of university and community members developing a set of guidelines for the ethical conduct of CEnR projects.

Key Points—The paper outlines the process of guideline development and lessons learned from this collaborative effort, which was based upon approaches and methods of community-based participatory research (CBPR).

Conclusions—The guidelines are included and may serve as a framework to be individualized by other partnerships. Our experience shows that the very process of review, revision, and engagement is extremely helpful in creating a framework that works for the specific communities and for establishing working relationships among the partners so that all stakeholders feel ownership and investment in the framework and the collaborative research efforts.

Keywords

Ethics; health care quality access and evaluation; community health partnerships; community-based participatory research; power sharing; process issues

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The Ethical Principles of Engagement Committee members and readers were the following:

- Co-Chairs Stephen Updegrave, MD, MPH, and Lois S. Sadler, PhD, PNP-BC, FAAN,
- Susan Bouregy, PhD, Jean Breny-Bontempi, PhD, MPH, Gina D'Agostino, MSN, Linda Dickey-Saucier, MS, Donna LaPaglia, PsyD, Jean Larson, MBA, Catherine McCaslin, PhD, Laura Minor, MS, PA, CPPR, Douglas Olsen, PhD, RN, Sara Rockwell, PhD, David H. Smith, PhD.
- The RWJCS Program Community Advisory Board included Sharon Bradford, MSW, MS, Laurie Bridger, MD, Maria Damiani, MPH, Jeannette Ickovics, PhD, Stephanie Spangler, MD, Paul D. Cleary, PhD, Yale Interdisciplinary Center for Bioethics, Julius Landwirth, MD, Rita Kolb, Alycia Santilli, MSW, Maurice Williams, and the Hill Health Center Patient Research Planning and Review Committee.

This article describes our experience with a community– university collaboration to create guidelines for researchers and community agencies wishing to engage in health and social/ behavioral research partnerships. The process of developing, vetting, and implementing the guidelines closely parallels the engagement process in CEnR and the “lessons learned” therefore may benefit others looking to strengthen community–university research relationships.¹ The documents that we developed are appended, and could be adopted or adapted to fit other communities. Throughout the process, it was clear that the ethics of respectfully including and working with an engaged community is integral to the design and implementation of a rigorous, meaningful CEnR partnership that would strengthen both research methods and community health outcomes.

The development of the guidelines iteratively integrated the ethical principles specific to the research approach of CBPR.^{1–3} We deliberately mirrored the CBPR process in the development and writing of the guidelines. This collaborative process brings into focus the intersection of research methods, community health principles, and research ethics. CEnR, defined more broadly as research that includes varying degrees of collaboration between community and academic partners, and the specific methodologic approaches defined in CBPR include essential elements of trust building and power sharing, finding shared interests, fostering co-learning and capacity building; building on strengths and using an iterative process, these elements ultimately result in the balance of research with action.^{1,4–7} The guidelines therefore reflect not only ethics, but also the roles and shared responsibilities of community and university research partners.

The process began as part of the foundational work of the Community Engagement and Research Core of Yale University’s Clinical and Translational Science Award (CTSA) program. Two members (one a researcher and one a community clinician) co-chaired the committee and proceeded with careful selection of committee members, including leaders and members representing key areas of the university and the community constituencies. A wide net was cast and people were invited to become either active members (attending meetings and writing drafts) or reviewers/commentators. An existing alliance with the Robert Wood Johnson Clinical Scholars Program (RWJCSP) at Yale engaged RWJCSP’s Community Advisory Board (CAB) members for committee participation, publicized the committee’s purpose, provided an initial ethical guidelines document that had been drafted by members of that CAB, and lent credibility and positive sanction for the newly forming committee. Both co-chairs were members of the RWJCSP CAB, illustrating the multiple “cross-overs” and relationships fundamental to the formation and work of the committee.

Committee members were recruited through outreach to health care, education, and social service agencies and to the local community and in-reach to potential university participants. The final committee included as community members consumers, city residents, public school representatives, representatives from health care agencies, and health care providers and social service agencies serving varying ages and community groups. University members included faculty from several schools within Yale experienced in clinical and CEnR, researchers from nearby universities, ethicists, university administrators, and institutional review board (IRB) representatives.

There were three community advisors with salary support from the CTSA who were members of the committee. These advisors included one health department leader and two community health center representatives. This support allowed for full participation of these members in the development of the guidelines as well as other community engagement work. This example of paid support has laid the ground work for evaluation of all research projects as to the level of support that will be provided to community partners. In many cases, the “salary support” for the university committee members comes from the general

institutional support for their scholarly activities. Some community partners are employed by agencies that likewise consider activities that enhance the health and welfare of the larger community to be part of their expected activities, and their salaries could also be considered to support their activities in building collaborative programs.

The committee began by reviewing the literature and ethical principles essential to the respectful engagement of community members in the research process. This was followed by a discussion of ethical and practical questions arising with shared decision making in CEnR. The committee considered ramifications of different definitions of the terms “community” and “CEnR,” discussed ethical principles central to CEnR, and reviewed literature on research ethics and CEnR case studies. This set the stage for discussing, planning, and writing working documents; developing plans for dissemination; and planning for integrating the guidelines into didactic research methods courses, IRB reviews, and/or consultative work on CEnR within the academic institution and surrounding or broader communities.^{6,8–10} The draft document was ultimately reviewed with the university provost’s office to garner university support, to enable use of the principles for teaching and training and to facilitate dissemination.

DEVELOPMENT OF THE ETHICAL GUIDELINES

Goals of this project included building more trusting and collegial research relationships between community agencies and university researchers, repairing the past failure of some researchers to involve community members in the research process, and co-creating a set of mutually acceptable, workable guidelines for conducting CEnR and thus enhancing the value and collaborative nature of health research conducted in this community. The guidelines were intended to orient and provide a framework for research partners (community and university) and to train future academic and community members regarding this method of collaborative health research, while remaining broad enough to be applicable to social and behavioral community research as well as health research. We found that researchers and community-based groups or health/social service agencies usually have different goals, missions (science and service, respectively), and operational constraints, which can lead to biases or to differences in how partners value research and thus hinder their ability to initiate a research partnership.^{8,11} The alignment between the groups determines how easy, or difficult, it may be to engage community representatives in the research process or as members of advisory committees.

The initial stages of the work included building mutual definitions of the words and concepts we were using. We began our collaboration with very different visions, and many of the early meetings were spent building an understanding of those different visions and realizing that we were using some very specific words very differently. For example, we spent time discussing and defining the “university” and the “community.” Another issue was distinguishing between research and health care and the development of health care policy. This was not a disagreement, but an area of different initial definitions and understanding between the community and university partners. There were also a number of conversations about the role of the university IRB in this process. There was some thought that the IRB would be the pivot point for ensuring that the guidelines were enforced. This perspective was counterbalanced by the belief that the university commitment to the collaborative process inherent in CEnR was greater than the purview of the IRB. It was also determined that having the IRB in a monitoring and enforcement role required services that the IRB could not provide, and moved the overall document into too narrow a focus.

In addition, committee members were concerned about the clarity and simplicity of the writing within the document, so that the final document could be understood by a wide

audience. Some members of the committee wanted to write a shorter version that was in lay language, whereas others wanted the depth and detail provided by a longer document. We compromised by writing an executive summary of the guidelines.

Defining Community

Many definitions and descriptions of communities exist; we found it helpful to consider broad, encompassing definitions. Committee members had many frank and lively discussions about the various ways to define and view the term “community.” The committee developed the following definition of community from our consultations with international research ethics papers,⁹ papers describing vulnerable communities,^{12–14} and general definitions of communities¹⁵:

- A defined geographic or political area such as a neighborhood, town, or region;
- A population that possess certain common characteristics such as race, ethnicity, age, or gender; and
- An entity that functions in society (and outside of the researcher’s own institution) such as a business, civic organization, educational facility, religious group, or governmental agency.¹⁶

These broad definitions recognize that communities have diverse forms, and may be unified by common interests, lifestyles, religious affiliations, or activities, or by other common characteristics such as geography, environment, gender, or ethnicity. Indeed, people usually belong to multiple, overlapping communities. The committee also came to realize that multiple “communities” also exist within a university in the various departments, centers, special interest groups, and collaborative teams. Just as there is no one individual who represents “the community,” there is no one individual or perspective that represents “the university” or “researchers.” There is the additional complexity of collectively deciding who represents “the community,” and who may speak for the community. These issues must be considered for each CEnR project or program because they vary widely from community to community. Some research studies and partnerships define narrow communities composed of people who share characteristics, languages, cultures, diseases, disabilities, or vulnerabilities that create special problems in engaging that community and/or in identifying appropriate spokespersons.^{2–4}

Describing Community Engagement

The process of engaging a community can take many forms. The process should help to bridge any existing gaps between groups or communities, such as town-gown dichotomies. Engagement must include two-way dialogue so that community members also shape and design research and researchers hear about health needs and issues that need attention.¹⁷ This process can involve advocacy groups and CABs and can include ensuring adequate representation by community members on university or health care agencybased IRBs.^{8,17}

Review of the Literature and the Ethics of CEnR

The committee began with a review of seminal ethical guidelines for research with human subjects. The individual-oriented ethical principles articulated by the Belmont Report (1979) are the bedrock of all IRB criteria and reviews and include the basic and non-negotiable principles of respect for persons, beneficence, and justice.¹⁸ These basic ethical principles of research with individuals must be expanded to apply to groups or communities. Shore¹⁹ reframed the Belmont Principles for CBPR to incorporate such elements as Ethics of Involvement, which involved partnership dynamics and process, the importance of negotiation, commitment, and so on, and issues of confidentiality and research skill as applied to the community. The Belmont principles were interpreted to consider respect for

persons as giving the community a voice in the research process; beneficence from an empowerment perspective; and justice as a “leveling of the playing field.”¹⁹

Writing the Document

Drafting of the guidelines began in 2006, before formation of the committee, when several community members of the RWJCSP CAB attended an RWJCS national meeting where issues of community engagement were discussed. Four community clinicians then wrote a draft document outlining several principles and approaches for the ethical engagement of community participants in health research. This early draft was refined and expanded by the committee, whose members worked diligently to include multiple perspectives and ideas in the guidelines, a collaborative process that was time intensive and required many meetings. The result was a document that was approved and endorsed by the local community and university where it was written, but was also broad enough to be useful for other communities. This document was posted on the Yale CTSA website, <http://www.yale.edu/hrpp/resources/docs/PrinciplesandGuidelinesforCommunityResearchPartnerships10-27-11.pdf>, and made available through several CTSA network sites and presentations as well as through the Partnership-driven Resources to Improve and Enhance Research website (www.researchtoolkit.org).

In May of 2009, a working conference Community-based Research: New Ethical Challenges held at Yale (sponsored by CARE, YCCI, Yale Interdisciplinary Center for Bioethics, and the Donaghue Foundation) gathered a national cohort of attendees from other CTSA and communities interested in ethical issues of university–community health research partnerships. A bibliography and a copy of the Ethical Principles and Guidelines for Community–University Research Partnerships were sent to all attendees. Attendees and speakers worked in groups to examine issues of defining community and CEnR and to discuss ethical principles in community–university research partnerships, methods for community and IRB review of CEnR proposals and training approaches, and materials for researchers and community partners regarding ethics and methods of CEnR. These groups developed reports that further vetted and supported the framework of the final document, and added additional insights and approaches (available at http://www.yale.edu/bioethics/research_careconf.shtml).

The Content of the Guidelines

The document begins with a description of the ethical principles inherent in the community–university research partnership process and brief definitions of terms and principles central to the document. This is followed by a description of the strategies and actions necessary to operationalize the principles, to make the document useful for both university and community research partners. The guidelines provide a detailed template that could be useful to community agency and university IRBs as they conduct ethical and regulatory reviews and to university or community-based researchers beginning to conceptualize a research question. The document is presented on the YCCI website (see <http://www.yale.edu/hrpp/resources/docs/PrinciplesandGuidelinesforCommunityResearchPartnerships10-27-11.pdf>) and an executive summary is presented in Table 1.

Keeping the Guidelines Alive and Meaningful

Committee members were dedicated to the idea that the final document not be placed on a shelf and forgotten. Ongoing dissemination includes sharing the guidelines with other CTSA and presenting them at national meetings and venues. Within the university and local CTSA Community Engagement and Research Core, the document has been included in proposal guidelines for pilot programs funding translational health research. Formal

incorporation into the University's Human Subjects Protection Program includes development of an on-line educational module using the guidelines. We also incorporate the guidelines into sessions in courses offered at Yale and other CTSA, into regional and national presentations and into consultations, and make the document freely and readily available through unrestricted web access. Community partners are invited to attend educational sessions presented by the human research protection program as well as various seminars such as the RWJCS program. We continue to be pleased with the extent to which these forums have facilitated reciprocal learning by fostering discussions between members of the university and the community. We continue to explore additional mechanisms for enhancing participation by community members in the research design, review, and approval process through CABS and agency-based IRBs and by soliciting greater participation of community members on university IRBs.

The guidelines document has been applied to a number of CEnR projects. Two examples include studies using the Photo-Voice qualitative research approach to understand and describe street violence as experienced by community youth, and to enhance primary care clinicians' understanding of their patients with severe and chronic mental illness. Other examples include several community-university collaborative research projects to prevent, screen, and treat obesity in young children. Additional examples include studies involving collaboration with international aid organizations to evaluate poverty remediation programs, including assessment of improvement to health outcomes.

LESSONS LEARNED: CHANGING THE CULTURE OF TRANSLATIONAL HEALTH RESEARCH

This process and the resulting principles and guidelines underscore the iterative relationship between ethics and sound methods of CEnR. As more clinical interventions are moved beyond labs and clinics and into communities, these guidelines and research partnerships may become more mainstream. At this point, however, there remains a need to help researchers learn to involve the community in defining the research question and in asking early in the process the following questions: "How can the research benefit from community input?" and "How can the community benefit from the research findings?" It is a slow but important process to integrate principles of CEnR into the work of IRBs, research training programs, and research courses across the university and the greater health sciences community. At the same time, it is important to convince busy clinicians and community members that integration of CEnR principles into the community and community agencies reinforces their key roles and the value of their contributions for programs of research. Finally, the university's awareness of these principles and their integration into the work of the CTSA guides the reciprocal training (between community partners and university researchers) that is integral to successful collaborative research partnerships.

There were several practical points and lessons learned from the process. This work takes time, patience, face-to-face presence, mutual respect, and ongoing commitment from all partners. Written memoranda of understanding help to formalize and structure working relationships among research partners and clarify roles and expectations. There are many small, practical points for both sides of the partnership to consider in planning and conducting meetings and negotiations, including careful attention to developing a shared understanding, with sensitivity about cultural or language issues, body language, verbal and nonverbal messages, and finding ways to have regular contact, whether that contact is by phone, videoconferencing, electronically, or face-to-face meetings. Ongoing connections and communication are essential, both to get the work done and to avoid the misunderstandings that are possible when working in multiple and complex contexts. Arrangements for food and parking as well as thoughtful scheduling of meetings to

accommodate many diverse academic, clinical, and community schedules offer examples of the small but important practical points that can facilitate success or contribute to the failure of fledgling partnerships.⁸

As community–university partners form working relationships with diverse communities, they may wish to adopt these guidelines. However, they may find it more valuable to adapt the guidelines for their own stakeholders. The process of forming a committee and conducting such a review of how the guidelines may or may not fit the unique characteristics and needs of their community, university, or health center in itself introduces new potential research partners to one another. The guidelines may serve as a template to be individualized, because our experience shows that the very process of review, revision, and engagement is extremely helpful in creating a framework that works for the specific communities and also for engaging and establishing working relationships among the partners so that all stakeholders feel ownership and investment in the framework and the collaborative research efforts that lie ahead.

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REFERENCES

1. Clinical and Translational Science Award. Principles of community engagement. 2nd ed.. Bethesda: National Institutes of Health; 2011.
2. Ross LF, Loup A, Nelson R, et al. Human subjects protections in community-engaged research: A research ethics framework. *J Empir Res Hum Res Ethics*. 2010; 5(1):517.
3. Blumenthal DS. Is community-based participatory research possible? *Am J Prev Med*. 2011; 40(3): 386–389. [PubMed: 21335275]
4. CDC. Principles of community engagement. Bethesda: Centers for Disease Control and Prevention Committee on Community Engagement; 1997.
5. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: Assessing partnership approaches to improve public health. *Annu Rev Public Health*. 1998; 19:173–202. [PubMed: 9611617]
6. Dalal M, Skeete R, Yeo H, Lucas G, Rosenthal M. A physician team’s experiences in community-based participatory research. *Am J Prev Med*. 2009; 37(6SI):S288–S291. [PubMed: 19896031]
7. Israel, BA.; Eng, E.; Schulz, AJ.; Parker, EA. *Methods in community-based participatory research for health*. San Francisco: John Wiley & Sons; 2005.
8. Norris KC, Brusuelas R, Jones L, Miranda J, Duru OK, Mangione C. Partnering with community-based organizations: An academic institution’s evolving perspective. *Ethn Dis*. 2007; 17:SI27–SI32.
9. Olsen D, vanderArend A, Drought T, et al. Ethical considerations in international nursing research: A report from the International Centre for Nursing Ethics. *Nurs Ethics*. 2003; 10(2):122–137. [PubMed: 12659484]
10. Silka L, Cleghorn GD, Grullon M, Tellez T. Creating community-based participatory research in a diverse community: A case study. *J Empir Res Hum Res Ethics*. 2008; 3(2):5–16. [PubMed: 19385742]
11. Bilodeau R, Gilmore J, Jones L, et al. Putting the “community” into community-based participatory research. *Am J Prev Med*. 2009; 37:S192–S194. [PubMed: 19896018]
12. Cochran P, Marshall C, Garcia-Downing C, et al. Indigenous ways of knowing: Implications for participatory research and community. *Am J Public Health*. 2008; 98:22–27. [PubMed: 18048800]

13. Mechanic D, Tanner J. Vulnerable people, groups and populations: Societal view. *Health Aff.* 2007; 26(5):1220–1230.
14. Grossman D, Agarwal I, Biggs V, et al. Ethical considerations in research with socially identifiable populations. *Pediatrics.* 2004; 113:148–151. [PubMed: 14702468]
15. Dunbar-Jacobs, J.; Hipps, L. CTSI community partners program. Washington (DC): National Institutes of Health; 2006.
16. Sadler, LS.; Updegrave, S.; Bouregy, S., et al. Principles and guidelines for community-university research partnerships. New Haven: Yale Center for Clinical Investigation; 2009.
17. Sugarman, J. Community-based research: New ethical challenges. New Haven: Yale Interdisciplinary Center for Bioethics; 2009. The ethics of engaging communities in health research.
18. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Belmont report: Ethical principles and guidelines for the protection of human subjects of research. Washington (DC): Department of Health, Education and Welfare; 1979.
19. Shore N. Re-conceptualizing the Belmont Report: A community-based participatory research perspective. *J Commun Pract.* 2006; 14(4):5–26.

Table 1**Principles and Guidelines for Community–University Research Partnerships: Executive Summary**

Create an Ethical Framework	A set of operating principles must be agreed upon that define the ways in which all research partners will conduct research ethically, and with respect for each other, the community, and the research participants.
Promote Diversity	Communities are diverse, and so research partners should ensure that community involvement is as broadly representative as possible. The university is also recognized as representing a diverse community.
Share Decision Making	Members of both the community and university should participate in the planning of research in its earliest stages as well as review and approval of community-based research.
Share Benefits	The resources, rewards, products and/or publications from community–university research partnerships should be shared among the partners.
Train Research Partners	It is essential to train community and university partners in the design and conduct of research studies within various community settings, so that each develops an understanding of the community and the research endeavor. This training should optimally be a joint and ongoing process.