Convergence Despite Divergence: Views of Academic and Community Stakeholders about the Ethics of Community-Engaged Research

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Purpose: Stakeholder engagement and community-engaged research (CEnR) are recognized as approaches necessary to promote health equity. Few studies have examined variations in stakeholder perspectives on research ethics despite the potential for meaningful differences. Our study examines the association between stakeholders' characteristics and their perception of the importance of 15 stakeholder-developed CEnR ethical statements.

Design: Quantitative analysis of close-ended Delphi survey.

Participants: We recruited a national, nonrandom, purposive sample of people who were eligible if they endorsed conducting CEnR in public health or biomedical fields. Participants were recruited from publicly available information, professional email distributions, and snowball sampling.

Main Outcome Measures: We designed our close-ended Delphi survey from the results of 15 CEnR ethical statements, which were developed from a consensus development workshop with academic and community stakeholders.

Results: 259 participants completed the Delphi survey. The results demonstrated that stakeholders' characteristics (affiliation, ethnicity, number of CEnR relationships, and duration of CEnR partnerships) were not associated with their perception of the importance of 15 ethical statements.

Conclusions: The strong agreement among stakeholders on these broad, aspirational ethical statements can help guide partnerships toward ethical decisions and actions. Continued research about variability among stakeholders' ethics perspectives is needed to bolster the capacity of CEnR to contribute to health equity. *Ethn Dis*. 2019;29(2):309-316. doi:10.18865/ed.29.2.309

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Introduction

Stakeholder engagement and community-engaged research (CEnR) are now recognized as essential approaches to improve public health and conduct health equity research.[1–3] Academics establish partnerships with assorted stakeholders who may be patients, advocates, community leaders, local residents, service providers, and funders.[2,4] Strong partnerships rely on the common CEnR values of social justice, common good, and equity. Yet, diverse viewpoints and agendas persist, particularly in the case of ethics where CEnR raises unique tensions.[2,4] CEnR aspirational ethics raise tensions about managing power dynamics, demonstrating community benefit, redressing historical exploitation, and building ethical cross-cultural relationships.[5,6] The purpose of our research was to examine potential convergence and divergence between academic and community perspectives about the ethical conduct of CEnR.

Background

CEnR academics and community leaders are advancing new ethics training programs targeting community partners,[3] streamlining review processes,[7,8] establishing community review boards,[9,10] and recommending refined ethics

standards,[11–13] to promote ethical CEnR practices. A growing body of research focuses on academic researchers' concerns about CEnR ethics,[1,11] yet community voices are less often represented. Ethical issues of trust, privacy/confidentiality, inclusion/exclusion criteria, scientific integrity, and recruiting friends and family were commonly raised by academic partners.[1,11] Scholars note that community partners, in contrast to academics, may shoulder additional ethical burdens because of their unique knowledge as insiders to the community where research is being conducted.[5,14]

The purpose of our research was to examine potential convergence and divergence between academic and community perspectives about the ethical conduct of CEnR.

Research is emerging that examines the variability among CEnR stakeholder perspectives.[15] For example, one study used in-depth interviews to reveal distinct scientific integrity issues raised by community- and university-based stakeholders.[16] Specifically, community partners highlighted power concerns such as academic partners wielding control over data (ownership of the data itself, as well as collection and analysis). In contrast, academic partners expressed concerns about career advancement and the time-intensive nature of CEnR. Another study found differences in stakeholders' perspectives on what leads to trust in CEnR partnerships.[17] Academic researchers, health care providers, and community members all rated "authentic, credible, and transparent communication" and "mutually respectful and reciprocal relationships" as the most important antecedents to trust in their partnerships. In contrast, community members rated "communication, credibility, and methodology to anticipate and resolve problems" and "sustainability" with greater importance compared with academic researchers and health care providers. As scientific integrity and relationships are aspects of the ethical conduct of research, this emerging body of research suggests that there are likely meaningful differences among stakeholders in regard to their perspective on the conduct of research.

Some ethics research recruited convenience samples from a single, local partnership, to examine community and academic differences;[6,11,18] thus unable to answer questions about generalizable differences among stakeholders. We found no study that quantitatively analyzed variability in CEnR ethics perspective related to stakeholder characteristics. With the importance of research ethics in CEnR partnerships, research is needed to examine if ethics concerns vary by stakeholders' characteristics, such as affiliation, racial/ethnic identity, and prior CEnR experience. Understanding the range of perspectives will be essential in disseminating guidelines for the ethical review and conduct of CEnR.

Study Aims

Our study sought to examine the association between stakeholders' characteristics (affiliation, ethnicity, experience with CEnR) and their perception of the importance of 15 CEnR ethical statements and to examine the variability in stakeholders' perception on the importance of the 15 CEnR statements. The 15 CEnR ethical statements are aspirational guidelines that were developed from a consensus development workshop with academic and community stakeholders.[19] Given the limitations of the existing literature, no specific associations were hypothesized. Our hypothesis was: Stakeholders' perceptions on the importance of CEnR ethical statements varies by stakeholder affiliation, ethnicity, number of CEnR partnerships, and duration of CEnR partnerships.

Methods

Participants and Setting

We recruited a national, nonrandom, purposive sample of people who were eligible if they endorsed conducting CEnR in public health or biomedical fields. Recruitment was from publicly available information, professional email

distributions, and snowball sampling. Details of the study design have been described elsewhere.[19] Briefly, we sent email to 1,213 individuals who were: corresponding authors of published articles; listed in the NIH Reporter system; personal contacts; and professionals on organizational contact lists. These professional email distributions lists were: Community-Campus Partnerships for Health; Community-Based Public Health Caucus and National Community-Based Organization Network; and community engagement, ethics and community engagement cores of Clinical and Translational Science Award Consortium. Corresponding authors were identified from relevant articles found through a PubMed and Scopus search; (search terms were community-based participatory research, community-based research, participatory research, consumer driven research, and community-engaged research AND ethics OR morals). Snowball sampling was used at the close of the survey by requesting that the survey be distributed to the recipients' collaborators. All study procedures were approved by the University of North Carolina Institutional Review Board and conducted according to approved procedures.

Data Collection

Increasingly used in CEnR research,[20] the Delphi technique solicits informed opinions on the ranking and ratings of a given topic to inform practice, policy, or clinical decision-making.[21] A strength of the Delphi method among the consensus methods is its use of an anonymous survey because social influence (eg, participant pressure to converge with group opinion) is reduced.[22] Consistent with accepted practices,[23] instead of an initial open-ended survey, we built our close-ended Delphi survey from the 1.5 day consensus development workshop with 11 academic and community stakeholders.[19] Because the statements were developed with stakeholders, not all statements use "ought" or "should," although the 15 ethical statements are intended to set normative standards.

The Delphi survey provided 15 ethical statements that participants were asked to rank (1st-15th, where 1st= most important and 15th= least important) and rate the importance of each statement (1-5, where 1= not at all important and 5= very important). The open-ended items allowed participants to add their own ethical statement and open comments. The 15 ethical statements were:

1. Researchers and communities strive for active partnerships that honor shared power and resources, co-learning and mutual respect.
2. Community-engaged research is responsive to the structural conditions responsible for poor health and deprivation and contributes to the improvement of fundamental participant and community welfare.
3. Community engagement should be guided by a broad conception of justice.
4. Community and academic researchers in partnership, determine whether and how proposed research is important, relevant, and valuable.
5. Those parties involved in community-engaged research (CEnR) should engage the community of interest in the planning, implementation and dissemination of research.
6. Researchers and communities should have transparent communication with one another to foster trustworthiness.
7. Research should be initiated after first gaining familiarity with the setting in which the research will be conducted.
8. In engaged research, attention must be paid not only to risks, benefits, and autonomy of individual research participants, but risks, benefits, and autonomy as they relate to communities.
9. Identification of potential participants should be informed by community and academic researcher expertise to ensure fair selection and scientific validity.
10. The process of obtaining consent should be informed by community and academic researcher expertise to take into account cultural, historical, and social context.
11. Communities should provide input as to what constitutes acceptable risks and benefits.
12. Researchers and communities are accountable for their presence and impact.
13. Findings and data should be accessible to every stakeholder in order to increase dissemination of results and support sustainability.
14. Community and academic researchers should aim for either the sustainability, responsible closure, or transition of projects.
15. Community and academic researchers should com-

mit to building and maintaining relationships over time.

Analysis

Student Newman-Keuls (SNK) was appropriate to test the variance in the rankings of the statements. Frequency statistics allowed examination of variance in ratings of statements. One-way analysis of variance (ANOVA) was appropriate to test the following null hypotheses:

1. H_0: There is no association between proportion of stakeholders' rating 5 for ethical statements and stakeholders' affiliation.
2. H_0: There is no association between proportion of stakeholders' rating 5 for ethical statements and stakeholders' ethnicity.
3. H_0: There is no association between proportion of stakeholders' rating 5 for ethical statements and stakeholders' quantity of CEnR partnerships.
4. H_0: There is no association between proportion of stakeholders' rating 5 for ethical statements and stakeholders' duration of CEnR partnerships. Missing data were removed for analysis.

Table 1. Participants by affiliation, race, ethnicity, gender, and location, N=259

Stakeholder characteristic	n	%
Affiliation		
Academic	118	45.56
Community	50	19.31
IRB or Bioethicist	19	7.34
Other	38	14.67
Missing	34	13.13
Race		
American Indian	8	3.09
Asian	7	2.70
Black or African American	50	19.31
Multi-Racial Identity	7	2.70
Native Hawaiian or other Pacific Islander	3	1.16
White	128	49.42
Missing	56	21.62
Ethnicity (Hispanic or not)		
Hispanic	39	15.06
Not Hispanic	183	70.66
Missing	37	14.29
Gender		
Female	177	68.34
Male	46	17.76
Missing	36	13.90
Location		
Rural environment	22	8.49
Suburban environment	29	11.20
Urban environment	173	66.80
Missing	35	13.51

Results

Two hundred fifty-nine participants completed the survey, as shown in Table 1.

Student Newman-Keuls (SNK) analysis found no statistically significant differences in the ranking of statements (mean ranking for each statement was in the range of 6.65-8.88); therefore, the ranking data were not analyzed by stakeholder characteristics. Also, there was no meaningful response or pattern of responses to the open-ended prompts to justify any further data collection or changes to the analysis plan.

Examination of response frequency showed low variability in the rating of the ethical statements. In response to the item "How important are the following statements to the ethical conduct of community engaged researcher," a sizeable por-

Table 2. Variance in stakeholder ratings of the importance of 15 ethical statements

	Rank					
Statement	**1, n (%)**	**2, n (%)**	**3, n (%)**	**4, n (%)**	**5, n (%)**	**0 or missing**
1. Researchers and communities strive for active partnerships that honor shared power and resources, co-learning and mutual respect.	1 (.39%)	5 (1.93%)	9 (3.47%)	39 (15.06%)	150 (57.92%)	55 (21.24%)
2. Community engaged research is responsive to the structural conditions responsible for poor health and deprivation and contributes to the improvement of fundamental participant and community welfare.	0 (0%)	5 (1.93%)	29 (11.20%)	52 (20.08%)	115 (44.40%)	58 (22.39%)
3. Community engagement should be guided by a broad conception of justice.	3 (1.16%)	4 (1.54%)	23 (8.88%)	38 (14.67%)	130 (50.19%)	61 (23.55%)
4. Community and academic researchers in partnership, determine whether and how proposed research is important, relevant, and valuable.	3 (1.16%)	4 (1.54%)	16 (6.18%)	57 (22.01%)	115 (44.40%)	64 (24.71%)
5. Those parties involved in community engaged research (CEnR) should engage the community of interest in the planning, implementation and dissemination of research.	0 (0%)	4 (1.54%)	3 (1.16%)	35 (13.51%)	160 (61.78%)	57 (22.01%)
6. Researchers and communities should have transparent communication with one another to foster trustworthiness.	0 (0%)	2 (.77%)	4 (1.54%)	27 (10.42%)	168 (64.86%)	58 (22.39%)
7. Research should be initiated after first gaining familiarity with the setting in which the research will be conducted.	0 (0%)	3 (1.16%)	16 (6.18%)	47 (18.15%)	133 (51.35%)	60 (23.17%)
8. In engaged research, attention must be paid not only to risks, benefits, and autonomy of individual research participants, but risks, benefits, and autonomy as they relate to communities.	0 (0%)	2 (.77%)	18 (6.95%)	40 (15.44%)	141 (54.44%)	58 (22.39%)
9. Identification of potential participants should be informed by community and academic researcher expertise to ensure fair selection and scientific validity.	1 (.39%)	10 (3.86%)	23 (8.88%)	52 (20.08%)	115 (44.40%)	58 (22.39%)
10. The process of obtaining consent should be informed by community and academic researcher expertise to take into account cultural, historical, and social context.	0 (0%)	6 (2.32%)	7 (2.70%)	44 (16.99%)	143 (55.21%)	59 (22.78%)
11. Communities should provide input as to what constitutes acceptable risks and benefits.	0 (0%)	3 (1.16%)	10 (3.86%)	55 (21.24%)	133 (51.35%)	58 (22.39%)
12. Researchers and communities are accountable for their presence and impact.	2 (.77%)	7 (2.70%)	14 (5.41%)	60 (23.17%)	116 (44.79%)	60 (23.17%)
13. Findings and data should be accessible to every stakeholder in order to increase dissemination of results and support sustainability.	0 (0%)	3 (1.16%)	18 (6.95%)	49 (18.92%)	131 (50.58%)	58 (22.39%)
14. Community and academic researchers should aim for either the sustainability, responsible closure, or transition of projects.	0 (0%)	5 (1.93%)	14 (5.41%)	51 (19.69%)	131 (50.58%)	58 (22.39%)
15. Community and academic researchers should commit to building and maintaining relationships over time.	0 (0%)	2 (.77%)	7 (2.70%)	40 (15.44%)	151 (58.30%)	59 (22.78%)

Rating scale: 1-5, where 5 = very important, 1 = not at all important.

Table 3. One-way ANOVA results

Relationships between proportion of ethical statements rated 5 ("very important") and stakeholder characteristics	F test statistic [a] (df 1, df 2)	Statistical Significance Yes/No (p<.05)
Proportion of ethical statements rated "very important" and stakeholders' affiliation	1.51 (3, 197)	No (.21)
Proportion of ethical statements rated "very important" and stakeholders' ethnicity	2.08 (1, 197)	No (.15)
Proportion of ethical statements rated "very important" and stakeholders' quantity of CEnR partnerships	.42 (3, 164)	No (.74)
Proportion of ethical statements rated "very important" and stakeholders' duration of CEnR partnerships	.48 (3, 164)	No (.70)

a. F test statistic is between-group differences divided by within-group differences as a means to evaluate whether there is statistically significant difference between groups.

tion of respondents (n = 144-168 [44.40%-64.86%]) endorsed "5" on a given statement (Table 2). Forty participants (15.44%) endorsed "5" on all 15 statements. The data were re-coded so stakeholder characteristic hypotheses could be tested to compare responses of "5" and "Not 5." Each rating had 55-64 (21.24%-24.71%) missing responses that were not included in the analysis.

Given the diversity of CEnR stakeholders and the ethical tensions inherent to CEnR in ensuring community benefit, managing power dynamics, these results show the strong agreement among stakeholders on these broad, aspirational ethical statements.

The results of the one-way ANOVAs were not statistically significant at a 5% Type 1 error rate (Table 3).

Discussion

The results demonstrated that stakeholders' characteristics (affiliation, ethnicity, number of CEnR relationships, and duration of CEnR partnerships) were not associated with their perception of the importance of 15 ethical statements. Participants endorsed the importance of all 15 statements, and the variability in the responses cannot be accounted for by the stakeholder characteristics we tested. Given the diversity of CEnR stakeholders and the ethical tensions inherent to CEnR in ensuring community benefit and managing power dynamics, these results show the strong agreement among stakeholders on these broad, aspirational ethical statements. This agreement on ethics can provide a substantial foundation for CEnR research and help guide partnerships toward ethical decisions and actions.

Nonetheless, our results differ from existing literature in that we found convergence in stakeholder perspectives as opposed to divergence. One possible explanation is that the ethical statements are broad guidelines, and stakeholders likely do have differing opinions when it comes to the actual implementation of those guidelines. Accordingly, tensions may arise not due to mismatches in values but due to the conflict in operationalizing, enacting, or upholding those values among diverse stakeholders. Awareness of common ethical ground could facilitate dialogue as stakeholders seek mutually satisfactory solutions for the conflicts they encounter.

Study Limitations

Future research to further examine potential differences and similarities may benefit from using forced-

choice responses that compare rating statements. Our study was limited in the variability of responses (eg, 40 participants [15.44%] rated all 15 statements as very important) and missing data. With online survey completion, participants could submit the survey with missing responses; thus, unintentional and/or intentional omissions were common. Our study also relied on non-random sample consistent with Delphi method. Unfortunately, due to limited variability in the data, we were not able to analyze differences by racial group, only ethnicity. We relied largely on the networks of the academy, which may have networks that mirror themselves rather than a diverse group with individuals from all racial groups. In the future, studies could benefit from random, stratified sampling to yield more generalizable results.

Conclusions

Just as researchers have found that trust and relationship building are important to CEnR,[17] consensus around ethics may also promote strong partnerships. Being aware of ethical convergence promotes solidarity among stakeholders engaged in an academic partnership and provides researchers with a guiding narrative for CEnR ethical success.

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Conflict of Interest

No conflicts of interest to report.

Author Contributions

Research concept and design: Hoover, Green, Richmond, Rennie, Corbie-Smith; Acquisition of data: Green, Richmond, Wynn, Nisbeth, Corbie-Smith; Data analysis and interpretation: Hoover, Tiwari, Kim, Green, Richmond, Wynn, Nisbeth, Rennie; Manuscript draft: Hoover, Tiwari, Kim, Green, Rennie, Corbie-Smith; Statistical expertise: Kim; Acquisition of funding: Hoover, Green, Richmond, Wynn, Corbie-Smith; Administrative: Green, Nisbeth; Supervision: Hoover, Richmond, Rennie, Corbie-Smith

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