Enhancing Stewardship of Community-Engaged Research Through Governance

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Objectives. We explored the relationship of community-engaged research final approval type (tribal government, health board, or public health office (TG/HB); agency staff or advisory board; or individual or no community approval) with governance processes, productivity, and perceived outcomes.

Methods. We identified 294 federally funded community-engaged research projects in 2009 from the National Institutes of Health's Research Portfolio Online Reporting Tools, Centers for Disease Control and Prevention's Prevention Research Centers, and Native American Research Centers for Health databases. Two hundred (68.0%) investigators completed a survey about governance processes and productivity measures; 312 partners (77.2% of 404 invited) and 138 investigators (69.0% of 200 invited) completed a survey about perceived outcomes.

Results. Projects with TG/HB approval had increased likelihood of community control of resources (odds ratios [ORs] ≥ 4.80). Projects with other approvals had decreased likelihood of development or revision of institutional review board policies (ORs ≤ 0.37), having written agreements (ORs ≤ 0.17), and agreements about publishing (ORs ≤ 0.28), data use (ORs ≤ 0.17), and publishing approval (ORs ≤ 0.14).

Conclusions. Community-engaged research projects with TG/HB approval had strong stewardship of project resources and agreements. Governance as stewardship protects community interests; thus, is an ethical imperative for communities, especially native communities, to adopt. (*Am J Public Health.* 2015;105:1161–1167. doi:10.2105/AJPH.2014.302457)

Researchers working with native communities (American Indian, Alaska Native, and Native Hawaiian peoples), other racial/ethnic minority communities, or other communities facing disparities that experience similar mistrust for past research issues, health inequities (e.g., gays and lesbians or people with disabilities), or both, have advocated the use of participatory research to enhance community health.[1–6] Such approaches include tribal participatory research, community-based participatory research, and participatory action research and are generally grouped as community-engaged research (CEnR). There is a continuum of engagement,[7] but CEnR that involves collaborative partnership and shared leadership between community members and (academic) researchers in all phases of the research can build capacity of all partners, create research that benefits the community, and enhance translation of research findings to the community.[8–13] These approaches have attraction because they can advance cocreation of the research, contribute culturally centered methods, and foster research capacity.[1,2,14,15]

Although CEnR approaches have appeal, they still require governance to provide protection, oversight, guidance, legitimacy, and community benefit. Governance over CEnR is complex and involves numerous practices and policies.[16,17] Historically, oversight responsibilities have been held by institutional review boards (IRBs) that uphold federal standards established by the Office for Human Research Protections.[18,19] Use of IRBs (e.g., university IRBs or Indian Health Service IRBs) for research oversight characterizes governance as regulation as the focus is on balancing the needs of protection of individuals from harm while trying to foster scientific innovation. However, when research partners consider other functions of governance alongside legal regulation (e.g., use of tribal governments or community-based review boards), the quality of research can be strengthened and more attention paid to the benefits and harm of the research for the community.[20–22]

In recent years, policymakers, CEnR researchers, and community organizations have advocated a broader perspective of governance, one that can be characterized as stewardship of research. Governance as stewardship enhances protection of the community, helps to foster research partnerships and appropriate access to and approval of research by community bodies, ensures benefit for the community, provides legitimacy of the research, shares responsibility for the research, provides community control, and builds research capacity in communities.[20–23] For example, when native communities steward research, new patterns emerge between academic and community partners that might involve (1) community and academic partners requiring and committing to oversight by a tribal council or community board, (2) review boards or tribal governments insisting the that project demonstrate benefits to the community (not just individuals), (3) all partners committing to tribal ownership of the data, and (4) all partners working to use data and disseminate findings following tribal review.[2,24–27]

Although nontribal communities do not have a tribal council for formal governance, they establish various governance mechanisms such as oversight by faith-based networks or leaders, health boards or public health offices, project advisory boards, or community partner boards.[21,28–30] Stewardship by these governing entities may involve (1) academic partners that engage in collaboration with the community to produce the research, (2) projects that use culturally relevant research designs and instruments to enhance the quality of the research, (3) projects that hire community members on research projects to build research capacity, and (4) academic partners that

encourage community engagement and participation.[2–4,21,28] In both native and nonnative communities, stewardship practices lead to enhanced trust of the research process by community partners, relationships that balance community and academic institutional power, IRB processes that reflect community interests and not just biomedical interests, inclusion of cultural frameworks that fit the community, and academic members committed to community engagement.[21,28,31]

Enhancing stewardship of research through governance has focused on several activities. First, increasingly, native and nonnative communities are asserting their roles in overseeing research by developing community IRBs and other forms of research oversight.[23,32,33] Second, research review can protect community knowledge by establishing protocols for oversight and can affirm tribal or community authority to approve and guide research that will benefit the community.[21,22,28–30,33,34] Third, the National Congress of American Indians[35–37] asserts that tribes, as sovereign nations, have regulatory authority over research that takes place on tribal lands and with tribal citizens. Several tribes have exercised governance by establishing research codes, research review boards, and formal agreements with research institutions, and some intertribal entities have established research oversight in urban and cross-tribal regions.[33,38]

Despite the expanded view of ethical issues within CEnR projects and an upsurge in community governance expectations from communities and some funders, there has been little research that has examined the role of governance in research specifically, as well as concerns that these processes might inhibit research. Some researchers and policy analysts suggest that tribal research review is perceived as slowing or blocking research development and dissemination.[25,35] A tension related to data ownership to ensure risks and benefits are considered for communities, individual research participants, and research funders also exists.

What has been lacking in these discussions to date has been research about the associations of governance with agreements, control of resources, productivity, and perceived outcomes of CEnR. Agreements are the accepted standards or protocols for the research partnership such as mission and objectives, group dynamics, and dissemination.[12,39] Control of resources is whether the community, academic institution, or both hire personnel and manage project resources.[12,40] Research productivity measures include garnering funding, disseminating scholarship, developing new measures centered in cultural or community perspectives, and establishing new research regulation.[3,23,28,30] These measures are important as the need to generate, disseminate, and regulate new knowledge and practices are core goals of funding agencies and, to a lesser extent, communities.

Perceived outcomes of CEnR focus on the contributions to health, and encompass changes in power relations, sustainability, community transformation, improved health of the community, and capacity building for individuals and agencies.[12] These outcomes are important as they are health outcomes or factors that enhance public health. Ultimately, the success of a CEnR project is determined by research productivity and improvement of health outcomes.

The notion of governance also has often been a source of mystery and conflict in research partnerships. We sought to foster understanding and provide context around governance as "stewardship" in research partnerships in both native and nonnative communities by focusing on the type of final approval of CEnR—the body or individual who endorsed and approved the project on behalf of the community and allowed it to continue. This approval is a key factor for legitimacy, community involvement, oversight, and guidance of the project.[26,35] Furthermore, the type of approval has not been studied, whereas the general oversight of research ethics through community or tribal IRBs has garnered recent research focus.[21,33,38] Examining the type of approval allows an exploration of how governance as stewardship balances needs for authority and accountability, control and capacity building, and protection and benefits.

METHODS

The purpose of this study was to explore the relationship of type of final approval of CEnR projects with governance processes (control of resources and agreements), productivity measures, and perceived outcomes. The study is part of a large mixed-methods research project called "Research for Improved Health" that aimed to understand partnering processes and outcomes associated with CEnR.[41] This study is the first large-scale empirical examination of governance of CEnR projects in the United States. Whereas the larger research project included qualitative data, this current study reports only the quantitative survey methods.

Design

The design involved 3 stages with objective information collected in the first stage and subjective information gathered in the second and third stages. First, we identified CEnR projects with federal funding in 2009 from the National Institutes of Health's Research Portfolio Online Reporting Tools (RePORTER),[42] Centers for Disease Control and Prevention's Prevention Research Centers (PRCs),[43] and Native American Research Centers for Health (NARCH) databases.[44] Specifically, project descriptions were searched by computer programming for keywords (community, community-based, participatory, tribal, AIAN [American Indian/Alaska Native], action, engagement, research, tribally driven, CBPR [community-based participatory research], CEnR, and PAR [participatory action research]) in various combinations. Team members then reviewed selected abstracts (n = 992) to determine inclusion as a CEnR project. Inclusion criteria included a research-focused funding mechanism with at least 2 years of funding remaining. Second, we invited principal investigators (PIs) identified in the first stage to complete a key informant survey (KIS) about their respective projects and also to identify academic and community partners. Third, we invited the PI and the academic and community partners identified to participate in a community engagement survey (CES) about perceptions of context, processes, and outcomes corresponding to a community-based participatory research conceptual model.[12] Only relevant information is presented here with more details on the larger project found elsewhere.[45–47]

Participants

We identified a total of 294 CEnR projects in stage 1; 200 PIs (68%) responded to the KIS

in 2012. Of these projects, 47 were located in native communities (single or intertribal communities) and 153 were located in other communities (including 24 Hispanic, 21 multiple, 20 African American, 7 Asian American, and 87 no specific ethnicity). Of the 200 respondents, 187 were PIs, 11 were key personnel, and 2 were other staff members. From the RePORTER, PRC, and NARCH databases, the average year of the current project was 4.73 years (SD = 2.08) and average total funding amount was $2.51 million (SD = $1.92 million). From PI report, the projects had an average length of partnership of 8.15 years (SD = 4.71), and 35 of the projects were descriptive, 125 were interventions, and 39 were other (usually a combination of both types).

The PIs nominated 404 partners (up to 1 academic and 3 community partners) to complete the CES. A total of 312 partners (77%) completed the survey in 2012. We invited the 200 PIs who completed the KIS to complete the CES and 138 (69%) participated. They could complete the CES immediately upon completing the KIS and the vast majority who participated did so. All surveys were completed with DatStat Illume version 4.11, a Web-based survey platform (DatStat, Seattle, WA). Participants were recruited through an invitation letter, provided a $20 incentive, and received up to 5 e-mail reminders and phone contact if needed.

Measures

The research team created 2 measures of governance. First, the PI was asked to identify who approved participation in this research project on behalf of the community and they could check all that apply:

1. agency leader, representative, board, or staff;
2. tribal government or health board or public health office (TG/HB);
3. individual community member(s);
4. project advisory board;
5. individual, no community decision; individual research participants give consent; and
6. other.

Second, they were asked about the control of resources, specifically hiring personnel, financial resources, and in-kind resources (community partner, academic partner, both, don't know). A third measure focused on whether there was a formal written agreement for the partnership and, if yes, whether it contained 14 features; these were adapted from a previously developed measure.[39]

Measures of productivity of the partnership came from the RePORTER, PRC, and NARCH databases,[42–44] or from items created by the research team. The databases provided information about total funding amount. Other items were created by the research team and asked of the PI: whether there were any publications (yes or no), whether the project resulted in revising or developing IRB policies (yes or no), whether the project resulted in the creation of new evaluation instruments (yes or no), whether the project yielded further grant money (yes or no), and the percentage of funds allocated to the community partner. We collected the items on funding and grant money because funding is an indicator of the capability to complete research goals. Community percentage of funding signals the degree to which the community has a stake in the research and whether they are able to effectively shape the research. Publications provide a key indicator of the ability to generate new knowledge. Changing or developing IRB policies may indicate the ability to steward the research for community as well as individual or science benefit. Finally, new measures signal an ability to customize and localize measures, which enhances research quality.

Measures of perceived outcomes included

1. degree to which the partnership had "synergy" (5 items; $\alpha = 0.90$),[14]
2. partner capacity building (3 items; $\alpha = 0.80$),[14]
3. agency capacity building (3 items; $\alpha = 0.87$),[14]
4. changes in power relations (5 items created for this study; $\alpha = 0.81$),
5. sustainability of partnership or project (3 items created for this study; $\alpha = 0.71$),
6. community transformation (4 items; $\alpha = 0.79$),[14] and
7. community health improvement (1 item created for this study).

The existing scale items came from a study of perceived outcomes for CEnR projects on mental health.[14] We tested all measures with confirmatory factor analysis to establish factorial validity and correlated them with other measures to establish convergent validity.[45] We averaged the responses across the project to create a single project score because there was a high level of agreement among the partners about the outcomes ranging from 0.65 to 0.78 on a measure of consensus of responses.[48]

As some of the measures were developed by the research team, it is important to discuss their validity. Our research team worked with a scientific advisory board made up of leading experts in CEnR. This board reviewed all measures and procedures and they made suggestions to enhance the quality of measures and the administration of the surveys. Thus, these items have at least face validity supported by expert review. This board also supported the decision to use the PI as a key informant about governance processes and productivity measures as the PI is the most informed about the project and an independent assessment of productivity and governance measures was beyond the budgetary constraints of the project. We subjected all surveys and procedures to a pilot test with cognitive debrief in 2 CEnR projects not included in the current sampling frame.

Data Analysis

We analyzed data with SPSS version 21.0 (IBM, Somers, NY), with all analyses on project-level data (information from databases and KIS as well as the averaged perceived outcomes from the CES). We completed analyses with logistic regression (binary or multinomial) for categorical variables. For the continuous variables, we conducted analyses of covariance tests. For all tests, total funding amount, length of the partnership, year of current project, and type of project (descriptive, intervention, or other) were covariates in the analyses.

There were few cases of missing data (< 3% of cases for all variables) and we replaced missing values for continuous variables by using multiple imputation of 5 values. We completed analyses for the pooled and each imputed value and they were consistent in terms of statistical significance.

RESULTS

The participants were asked to describe the nature of the agreements governing the project.

Slightly more than three quarters of the sample (n = 152) had a formal written agreement, 40 had verbal agreements, and 8 had no agreement. Participants also reported the type of final approval: agency leader or staff (e.g., health or education agency; n = 114), project advisory board (n = 70), individual (n = 59), TG/HB (n = 45), and no decision on behalf of the community (n = 25). We coded the responses into 3 categories: (1) TG/HB with or without other approvals (n = 45; 35 in native communities, 10 in nonnative communities); (2) agency or advisory board without TG/HB (n = 117; 10 in native communities, 107 in nonnative communities); and (3) individual or no community decision without TG/HB or agency or advisory board (n = 37; 1 in native communities, 36 in nonnative communities). Projects based in native communities were less likely than projects in other communities to have an advisory board (odds ratio [OR] = 0.03; 95% confidence interval [CI] = 0.01, 0.07) or individual or no decision (OR = 0.01; 95% CI = 0.001, 0.07) relative to a TG/HB.

Table 1 displays the results of the multinomial regressions to examine the associations of type of final approval with control of resources. Compared with TG/HB approval, projects approved by agency staff or advisory board or individual or no decision had a greater likelihood of having academic control or both community and academic control compared with community control of hiring and financial resources. Because there was a problem with convergence of the multinomial model for in-kind resources, we compared TG/HB with any other type of control. Relative to TG/HB approval, any other type of approval was associated with greater academic control or both community and academic control of in-kind control of resources.

Table 2 displays the results of the binary logistic regression to examine the associations between type of final approval and agreements and productivity measures. Compared with TG/HB approval, other types of final approval were associated with a decreased likelihood of having written agreements, agreements on publication or authorship, agreements on intellectual property, agreements on data use or ownership, and agreements on final authority to publish. There were 2 significant differences in productivity. First, revision or development of IRB policies was about 2.75 times more likely to occur with TG/HB approval than either agency or advisory board approval or individual approval or no decision to approve. Second, projects approved by a TG/HB (mean = 48.30; SD = 30.27) had a higher percentage of funds allocated to the community partner than agency or advisory board approval (mean = 34.13; SD = 21.18; $P = .003$) or individual or no decision (mean = 35.18; SD = 27.58; $P = .028$). There were no significant differences in perceived outcomes.

TABLE 1—Association of Final Approval and Control of Resources in 200 US Community-Engaged Research Projects With Federal Funding in 2009

Type of Shared Resources and Type of Control	Agency or Advisory Board,[b] OR (95% CI)	Individual or No Decision,[b] OR (95% CI)	Agency, Advisory Board, Individual, or No Decision,[b] OR (95% CI)
Hiring			
Academic[a]	7.05 (1.96, 25.36)	25.24 (2.60, 245.34)	
Both[a]	5.58 (1.91, 16.26)	11.09 (1.29, 95.34)	
Financial resources			
Academic[a]	16.48 (2.98, 90.98)	10.41 (1.10, 98.83)	
Both[a]	15.66 (3.08, 78.55)	8.89 (1.02, 77.46)	
In-kind resources			
Academic[a]			5.27 (1.22, 22.84)
Both[a]			4.80 (1.65, 13.97)

Notes. CI = confidence interval; OR = odds ratio. Control for length of time in partnership, length of time in the project, total funding amount, and type of project. Projects found in National Institutes of Health's Research Portfolio Online Reporting Tools, Centers for Disease Control and Prevention's Prevention Research Centers, and Native American Research Centers for Health databases.

[a]Compared with community control.

[b]Compared with health board or tribal government.

DISCUSSION

Having TG/HB approval, compared with other types of approval, was associated with greater community control of resources, greater data ownership, greater authority on publishing, greater share of financial resources for the community partner, and an increased likelihood of developing or revising IRB policies. Furthermore, there was no relationship with other productivity measures or perceived outcomes, such as sustainability, perceived agency or personal benefits, community transformation, or health outcomes. Overall, these results provide empirical evidence in support of the need for strong governance—stewardship and regulation—over research to ensure community benefit and control, expressed as greater community-driven agreements, access to resources, and development or revision of IRB policies.[2,17,21,23,33,38] However, the importance of type of final approval should be interpreted in the context of the community.

For native communities, these findings suggest that TG/HB approval provides benefit to the community in terms of control and share of resources and also monitoring data use and authority over dissemination of results.[2,21,26,27,33,38] These benefits are in addition to the need to establish trust and to demonstrate respect for tribal institutions and sovereignty.[16,18,26] The findings demonstrate that the survey respondents believe that community engagement and governance benefits the community and the research processes. Specifically, governance in native communities includes aspects of stewardship (e.g., benefit to the community through increased resources and control) and research regulation (e.g., data use or ownership). Furthermore, such findings provide justification for policy organizations[35] and researchers[33,38] to advocate community control through TG/HB oversight of CEnR projects and support the stewardship perspective of governance.

TABLE 2—Association of Final Approval With Agreements and Productivity in 200 US Community-Engaged Research Projects With Federal Funding in 2009

Factors	Agency or Advisory Board,[a] OR (95% CI)	Individual or No Decision,[a] OR (95% CI)
Agreements		
Written agreement	0.21 (0.07, 0.68)	0.17 (0.05, 0.60)
Distribution of funds	1.68 (0.71, 3.95)	0.75 (0.26, 2.17)
Mission statement	0.63 (0.26, 1.52)	1.01 (0.32, 3.26)
Objectives	0.98 (0.22, 4.48)	0.40 (0.08, 2.10)
Partner roles	1.61 (0.38, 6.83)	0.54 (0.12, 2.52)
Decision-making process	1.15 (0.52, 2.52)	0.73 (0.26, 2.06)
Conflict resolution	1.04 (0.45, 2.37)	0.62 (0.20, 1.95)
Publication or authorship	0.28 (0.12, 0.69)	0.23 (0.07, 0.72)
Intellectual property	0.23 (0.10, 0.56)	0.37 (0.13, 1.11)
Data use	0.17 (0.05, 0.53)	0.17 (0.04, 0.63)
Where published	0.87 (0.29, 2.63)	0.76 (0.15, 3.80)
How authorship determined	1.27 (0.44, 3.68)	1.05 (0.23, 4.71)
Final authority on publications	0.14 (0.03, 0.77)	0.11 (0.01, 0.81)
Student access to data	1.34 (0.50, 3.59)	0.37 (0.09, 1.55)
Productivity		
Any publications	1.34 (0.62, 2.90)	1.69 (0.62, 4.61)
Additional funding	1.97 (0.94, 4.11)	1.21 (0.49, 3.00)
Develop measures	1.37 (0.55, 3.39)	0.70 (0.24, 2.06)
Develop or revise IRB policies	0.35 (0.17, 0.74)	0.37 (0.15, 0.93)

Note. CI = confidence interval; IRB = institutional review board; OR = odds ratio. Control for length of time in partnership, length of time in the project, total funding amount, and type of project. Projects found in National Institutes of Health's Research Portfolio Online Reporting Tools, Centers for Disease Control and Prevention's Prevention Research Centers, and Native American Research Centers for Health databases.
[a]Compared with health board or tribal government.

These findings also have implications for governance in nonnative communities. Most nonnative communities do not have formal government bodies for project oversight (although there are some public health office or health board approval protocols in nonnative communities). There may be agencies that partner with the academic community or an advisory board constituted to oversee the project, but these bodies tend not to have the strong oversight consistent with that of a tribal government or government agency such as a health board. Certainly nonnative communities cannot duplicate the formal governing bodies of tribes, but there has been growing advocacy for community IRBs or research review boards by organizations such as the Community–Campus Partnerships for Health[21,22,32] and the current findings lend further support for this advocacy given the increase in protection and control for the community. However, nonnative communities have to weigh the benefit of formal governance with the costs to develop such governance. Rather than developing formal governing bodies, nonnative community members could encourage project advisory boards and individuals to consider control of resources, share of resources, and formal agreements (e.g., data ownership and use) as they develop partnerships with academic organizations to steward the project and provide increased benefit to the community.

Although this study was a census of CEnR projects federally funded in 2009 and had a strong response rate, there are limitations in the study. Because of constraints in survey length, we were not able to explore productivity measures in depth. We did not have measures of time for community review, number of publications from the project, or perceptions about the benefit and cost of governance. Furthermore, the lack of independent confirmation of governance and productivity measures means that results should be interpreted as perceptions about these processes and not objective "facts." Thus, we were not able to establish whether stewardship results in costs or gains to research productivity. In addition, the PI nominated partners for the CES and this may have introduced bias into the perceived outcomes. Finally, there were not sufficient numbers of projects in native and nonnative communities across the various types of approval to allow for more nuanced analysis of how governance operates in these communities.

In conclusion, we explored the governance of federally funded CEnR projects in 2009 and provided a description of how type of approval was associated with governance processes, research productivity, and perceived outcomes. Specifically, having a tribal government or government-type agency approval was associated with more control and share of resources for communities, greater level of formal agreements about data use and research dissemination, and revision or development of IRB policies. These aspects of governance focus on stewardship as well as research regulation. Understanding the nature of governance as stewardship rather than just regulation is important as it helps show reasons why native and nonnative communities may want strong research oversight and how they might implement this oversight. It also helps to counter some misperceptions that governance is only focused on research regulation and is only an impediment to productive and effective research to address health outcomes and health disparities.

Overall, this study suggests an ethical imperative for communities (especially native communities and other vulnerable populations) to adopt a model of governance focusing on stewardship in light of past historical ethical violations and events and the opportunity to benefit the community and provide legitimacy of research. ■

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Contributors

J. G. Oetzel conceptualized the article and led data analysis and article writing. M. Villegas, H. Zenone, and E. R. White Hat participated in conceptualization, data interpretation, and writing, editing, and reviewing the article. N. Wallerstein and B. Duran co-led research design and participated in writing, editing, and reviewing the article.

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Human Participant Protection

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