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Ethics and Science in the Participatory Era: A Vignette-Based Delphi Study

Elizabeth Bromley, M.D., Ph.D.*,

Associate Professor in Residence, Semel Institute Center for Health Services and Society, Department of Psychiatry and Biobehavioral Sciences, University of California, Los Angeles, Research Psychiatrist, Desert Pacific MIRECC, West Los Angeles VA Healthcare Center, 10920 Wilshire Blvd, Los Angeles, CA 90024

Lisa Mikesell, Ph.D., and

Assistant Professor, Department of Communication, Institute for Health, Health Care Policy and Aging Research, Rutgers University, 4 Huntington Street, New Brunswick, NJ 08901-1071

Dmitry Khodyakov, Ph.D.

Senior Behavioral/Social Scientist, The RAND Corporation, 1776 Main Street, PO Box 2138, Santa Monica, CA 90407-2138, Phone: +1-310-393-0411x 6159

Abstract

Participatory researchers rely on relationship-based ethical considerations to address ethical challenges, but little is known about how these considerations shape day-to-day decision-making. We presented vignettes describing ethical dilemmas to health researchers with varying degrees of experience in participatory research in an online modified-Delphi panel. Panelists rated potential solutions to dilemmas and provided rationales for choosing solutions in text boxes and discussion boards. Panelists agreed on a preferred solution for three of five vignettes. Panelists indicated that ethical research decision-making should be inclusive of diverse perspectives. Panelists prioritized scientific goals above participatory ones and viewed tenets of scientific validity as value-free. Panelists indicated that participatory research ethics would be difficult to codify, but that vignette-based learning could support didactic objectives.

Keywords

Participatory Research; Research Ethics; Vignette Research; Modified Delphi Panel

INTRODUCTION

A significant shift in research practice since the 1990s has been the growth in involvement of lay individuals (i.e., non-scientists) in the work of professional science (Cornwall & Jewkes, 1995). Several systematic models of participatory research refined in recent decades are now in wide use, including social action research, community-based participatory research, community-partnered participatory research, and patient-centered research (Cargo &

* Corresponding author ebromley@mednet.ucla.edu.

Mercer, 2008). In these models, researchers work with patients, community members, patient advocates, service providers, policy makers, payers, and other stakeholders as equal partners in most or all stages of the research process (Minkler & Wallerstein, 2008). In addition, many features of participatory approaches are now used in health research broadly where research has pragmatic or practice-relevant aims, such as increasing healthcare effectiveness, offering guidance on health decision-making, reducing disparities, or speeding the adoption of research in practice (Sugarman, 2016). Participatory practices are seen as strategies to improve research recruitment, increase the relevance of research findings to the public, and facilitate the adoption of research findings in practice (Hebert, Brandt, Armstead, Adams, & Steck, 2009; Schmittiel, Grumbach, & Selby, 2010). Many major U.S. health research funders expect some element of stakeholder involvement in research design, execution, and/or dissemination (Monahan et al., 2003; National Priorities for Research and Research Agenda, 2012; Tallon, Chard, & Dieppe, 2000; Wynne, 2006). “Engaging communities in research” is a key goal of the National Center for Advancing Translational Science (NCATS) at the National Institutes of Health (NIH) (Communities and Research, 2015). The Patient-Centered Outcomes Research Institute (PCORI) has placed a “strong emphasis on engaging patients and the broader healthcare community in all our work” (National Priorities for Research and Research Agenda, 2012, p.10). As stated in a report commissioned by the Agency for Healthcare Research and Quality (AHRQ), “Stakeholder involvement...helps ensure that [AHRQ-funded research] responds to relevant and important issues...develops products that are accessible and user-friendly, and...ultimately reaches its intended audiences” (Mallery et al., 2012, p.i). Consensus-building activities (Domecq et al., 2014; Principles of Community Engagement, 2011), substantive participant involvement in governance, and timely feedback of results to participants are key features of participatory research approaches and now have been adopted as critical priorities for the NIH Precision Medicine Initiative (*Precision Medicine Initiative: Privacy and Trust Principles*, 2015). Thus, it is possible to speak of a new participatory era in health research in which public engagement is seen to be important in the day-to-day tasks of knowledge production once reserved exclusively for scientists.

The broad adoption of participatory approaches has important but uncertain implications for research ethics (Brugge & Cole, 2003; Khanlou & Peter, 2005). For instance, in participatory research approaches, formal oversight through Institutional Review Boards (IRB) and traditional ethical principles like those outlined in the Belmont Report are understood to provide only a starting point for ethical practices. Many participatory researchers report that they confront novel ethical dilemmas that are beyond the scope of academic IRBs or impossible to resolve based on the Belmont principles (Malone, Yerger, McGruder, & Froelicher, 2006; Shore, 2007; Wilson, Kenny, & Dickson-Swift, 2017). In many participatory research projects, ethical priorities are neither determined *a priori* nor rigidly codified (Kraemer-Diaz, Spears Johnson, & Arcury, 2013). Participatory researchers adopt oversight procedures (e.g., community research review boards) and ethical priorities through local consensus that may be project-specific (Cordner, Ciplet, Brown, & Morell-Frosch, 2012; Stellefson, Paige, Alber, Barry, & James, 2015). Moreover, in participatory research, the time-limited role played by lay individuals through service as research *subjects* has given way to a concept of non-scientist stakeholders (including those who give data) as

full-fledged *participants* in the research enterprise (Bromley, Mikesell, Jones, & Khodyakov, 2015). This has had ethical implications, including but not limited to reformulations of informed consent (Skinner et al., 2015) and the foregrounding of issues like trust, transparency, and bidirectional learning in concepts of ethics (Khodyakov, Mikesell, Booth, Schraiber, & Bromley, 2016). When confronted with ethical dilemmas, participatory researchers say that research ethics “can be practically applied by building relationships, following participatory processes, developing locally relevant principles/codes of ethics,” and above all through “the centrality of trusting and respectful relationships between community members and researchers,” (Shore, Wong, Seifer, Grignon, & Northington Gamble, 2008, p. 2) or what Banks and colleagues (Banks et al., 2013) call “relationship-based” ethics.

In this paper, we examine the ethical implications of the adoption of participatory approaches to conducting research. We recruited health science practitioners with expertise in conducting different types of translational research and with varying degrees of expertise in participatory research and confronted them with dilemmas common on participatory teams. We used an innovative online modified-Delphi platform (Dalal, Khodyakov, Srinivasan, Straus, & Adams, 2011) to present vignettes describing real-world ethical dilemmas and their potential solutions. Vignettes are used widely to train researchers in the responsible conduct of research (McCarron & Stewart, 2011) and have been used to discriminate aspects of ethical decision-making (Lau, 2010; Mah, Taylor, Hoang, & Cook, 2014; Roberts et al., 2005). Panel members rated four solutions to five vignettes and engaged in a moderated online discussion about the rationales underlying their ratings. Guided by our own prior research and the findings in the literature described above, we designed vignettes and solutions that would elicit views of ethical choice where the norms of scientific practice and participation may come into conflict. We also designed vignettes that could elicit the ways in which features of relationships such as trust or respect could contribute to ethical decision-making. We analyzed their ratings and comments to elucidate the valuations that shape everyday ethical decision-making within a diverse research team (Schoenberg & Ravdal, 2000). We use these findings on ethical decision-making to anticipate how the norms, policies, and principles that currently structure health research ethics could be adapted to accommodate participatory approaches. In keeping with this aim, we review strategies for education in the responsible conduct of participatory research that may help to support the growth of participatory approaches in health research (Callahan & Jennings, 2002; Stellefson et al., 2015).

METHODS

Participants

As is typical for expert panels (Hasson, Keeney, & McKenna, 2000), we used a purposeful maximum variation sampling approach to avoid one-sidedness of representation of topics. We sought to engage translational science researchers from both academic and community sectors with varying degrees of experience in participatory research. By inviting participants through diverse channels described below, we aimed to recruit those who were merely curious about using participatory approaches to those with extensive experience in

participatory research models. Maximizing variation helps identifying unique perspectives and shared patterns that may be especially significant for having emerged from a diverse sample (Patton, 2002). Also, the increase in the use of participatory approaches in health research means that not only “expert” but also “novice” perspectives on ethical decision-making will shape norms and practices. To ensure that we solicited input from health researchers working on varied topics, we reached out to translational researchers conducting “bench to bedside” as well as “bench to curbside or countryside” studies (Sofaer & Eyal, 2010). We chose to recruit among translational researchers because the field today includes a wide array of researchers from basic scientists and epidemiologists to comparative effectiveness and public health researchers who are focused on moving research findings into clinical practice and to communities (Smith & Blumenthal, 2013; Westfall, Mold, & Fagnan, 2007).

We accessed NIH Reporter and the PCORI website to identify principal investigators (PIs) of ongoing translational research projects funded through R01 and R21 NIH grant mechanisms or PCORI’s Assessment of Prevention, Diagnosis, and Treatment Options mechanism as of December 2013. We also invited the first authors of the 25 “hottest” and “most viewed” articles published in *Translational Research* and *Implementation Science* journals, respectively. We contacted members of two Clinical and Translational Science Institutes, Community-Campus Partnerships for Health, the Community Based Public Health Caucus of the American Public Health Association, and the National Community-Based Organization Network. We encouraged respondents to nominate colleagues to participate. A total of 108 individuals expressed interest in participating by completing a study registration form, which included questions about demographics, professional background, and research experiences. Based on our prior experience recruiting for discussions of ethics in participatory research, we anticipated challenges recruiting researchers without considerable experience or strong commitment to use of participatory models of research (e.g., CBPR, CPPR) [author reference]. Consequently, to broaden the perspectives included, we minimized cues in our recruitment materials that would indicate that such experience or commitment was preferred. To minimize recruitment bias, we asked one question (“Do you have prior experience in conducting community-engaged research?” [Yes/No]) to determine whether the individual may have used participatory research approaches in the past. To minimize response bias, we did not provide a definition of participatory research or community-engaged research to potential participants to allow them to make their own assumptions about the nature of participatory research. While many study designs ask researchers to reflect on choices made in prior research projects (Chantler et al., 2013), we hoped to use vignettes to elicit responses independent of a particular project and reflective of general approaches, and therefore did not include questions about prior participatory projects.

Panel Design

We used an online modified-Delphi panel approach and collected data using the ExpertLens platform (Dalal et al., 2011). This platform helps explore the existence of consensus among diverse groups of participants and has been used in more than a dozen studies to engage diverse stakeholders in activities like developing research agendas (Claassen et al., 2014)

and defining emergent concepts (Rubenstein et al., 2014). Individuals participate online at a time convenient to them. The [author reference IRB] approved the study protocol.

Because the number of registered participants (n=108) exceeded the recommended size for ExpertLens panels (Khodyakov et al., 2011) we used background information to assign participants to two panels. We created panels that differed in composition to vary the viewpoints to which participants were exposed during the panel. We randomly assigned 54 researchers with experience in participatory research working at universities and non-profit research institutions to an “academic” panel. We assigned the remaining researchers, including academic researchers, healthcare professionals, and representatives of community agencies and healthcare organizations, some of whom had prior experience with participatory research, to a “mixed” panel. While the academic panel (AP) helped us explore the perspective of researchers with participatory experience, the mixed panel (MP) helped us investigate the perspectives of diverse participants from stakeholder groups typically represented on a participatory research team.

Vignettes

We developed, pretested, and presented to panelists vignettes that described common dilemmas in participatory research. Vignette methodologies are commonly used to clarify individuals’ judgments and suggest actions they would take in context (Barter & Renold, 1999). Through narrative representations of real-world scenarios, vignettes provide a window onto everyday decision-making and the valuations behind them (Atzmüller & Steiner, 2015; Hughes & Huby, 2002).

To ensure that vignettes reflected realistic ethical dilemmas, we drew on previous interview data from community-engaged researchers on common ethical challenges [author reference]. We used tallies of interview content about challenges encountered in community-engaged research to draft several candidate vignettes about frequently mentioned challenges (e.g., selecting culturally appropriate study instruments) as well as types of dilemmas those challenges reflected (e.g., balancing priorities of research rigor and participatory processes). Through review with the study team, the vignettes were narrowed to five addressing three types of dilemmas: 1) *research decisions*, such as how to collect data and report study findings, 2) *resource management* decisions including budget allocation and fairness of incentives, and 3) *relationships*, for instance, how to manage interpersonal conflict on the team (see Appendix).

Vignettes were designed to engage panelists in a short story about common dilemmas. Proposed solutions aimed to further panelist involvement in the story in alternate directions, rather than force a choice between solutions that might be judged as right or wrong. We maximized the differences between solutions by catering to different sides of a participatory research team. One solution was written to emphasize community concerns, such as respecting the needs of those in the community where data would be collected. A second solution was written to stress academic concerns, such as timely completion of high-quality research and publication in peer-reviewed, academic journals. A third solution offered a compromise that balanced but did not satisfy all stakeholder preferences. A fourth solution portrayed conflict avoidance by muffling conflict with a temporary solution. We recognized

these to be artificial constructions of opposing priorities but sought solution options that would generate dialogue and elicit panelists' attitudes to various aspects of dilemmas. To refine vignettes and maximize distinctions between the solutions, four experienced researchers – two from academic or non-profit research institutions and two from community-based organizations – reviewed each.

Each panel completed a three-round ExpertLens process between 3/31/14 and 5/12/14. Participants performed two tasks. In a first task, they rated the applicability of ethical principles commonly practiced in community-engaged research to translational research. We reported these results elsewhere [author reference]. Here we report on the second task. In Round One, participants used 9-point Likert-type scales to rate solutions to each vignette on three dimensions: *appropriateness* (whether the solution was the right or wrong action to take), *desirability* (how satisfied one was with the solution) and *effectiveness* (whether the solution would resolve the dilemma). They were asked to explain their ratings using open text boxes. In Round Two, participants saw how their Round One responses compared to those of other panelists and reviewed the group results (distribution of responses, group medians) for each rating criterion. The ExpertLens system showed simple statements describing whether or not agreement was reached and how the group rated each solution (i.e., positive, negative, or uncertain, as described below). In Round Three, panelists re-answered Round One questions in light of Round Two feedback. Between rounds, participants engaged in discussion using asynchronous and anonymous online discussion boards. Authors posted questions and comments for panelists, aiming to elicit reasons for preferring or not preferring each solution. Five randomly selected participants who completed all study rounds received a Kindle reading device as a study incentive.

Data Analysis

To determine the final group rating for each solution, we applied the method described in the RAND/UCLA Appropriateness Method Manual (Fitch et al., 2001) to the analytic sample of responses, which included Round Three responses of those participants who provided them and Round One responses of those who did not answer a given question in Round Three. As in another publication that used the data from these panels [author reference], we combined responses because there were no statistically significant changes in panel means between the two rating rounds, and the average difference in mean values was .4 on the 9-point scale.

A solution was considered “positive” (e.g., appropriate, desirable, or effective) if: (1) less than a third of all responses to a given question were in the lower tertile of response categories (1–3 on the 9-point rating scale) and in the upper tertile (response categories 7–9) (i.e., responses were not bimodally distributed) and (2) the group median fell into the upper tertile (response categories 7–9). If the distribution was not bi-modal as described above and the group median fell into the lower tertile (response categories 1–3), the group decision was “negative.” If, however, the median fell into the middle tertile (response categories 4–6), the decision was “uncertain.” We analyzed rating data for each panel and for each question separately. We then compared the panel ratings to determine “positive” solutions in both panels for each question. We examined whether each dilemma had a “preferred” solution.

We considered a solution to be “preferred” only if *both* panels considered it to be appropriate, desirable, and effective.

We analyzed qualitative data from text boxes and discussion boards, using the former to identify key perspectives and the latter to generate final themes. First, two authors (XX, XY) organized text box comments by rating for each solution and developed a preliminary set of codes to mark common and salient viewpoints. Then, two authors (XX, YZ) refined the codebook by reviewing all discussion board comments. Comments corresponding to each code were summarized, comparing within and across panels to identify differences and commonalities and to refine summaries of each code. Then, codes were grouped conceptually into themes and subthemes that reflected shared meanings and patterns in preferences for solutions (Ryan & Bernard, 2003). Unique perspectives shared with no other or a small number of panelists were flagged to ensure complete representation of all comments from discussion boards. All authors reviewed coding and thematic results to ensure consistency and comprehensiveness; disagreements were discussed until consensus was achieved. Finally, the first author compared final themes against all text box comments to validate that themes provided a comprehensive representation of common viewpoints.

RESULTS

Of 108 registered participants, 63 (58%) participated in our study, 33 in the academic panel (AP) and 30 in the mixed panel (MP). Of these, 58 (54%) provided responses in the vignette component (task 2) of the panel, 31 in the AP and 27 in the MP. Participant demographics for all registered participants are described in Table 1. There were no statistically significant differences in demographic characteristics between participants and nonparticipants. Eighty percent of the MP and 100% of the AP reported previous experience with participatory research. We achieved reasonable variation in the types of research conducted by panelists, with 44% conducting population health research and 30% conducting treatment or intervention research. Twenty-two percent of panelists were health services or implementation science researchers. Only 3% of panelists conducted pre-clinical or bench research, a field with low penetration of participatory approaches.

Table 2 shows that a “preferred” solution was identified in three out of five vignettes. Two of these vignettes described ethical dilemmas related to making research conduct decisions and one described a relationship dilemma. Neither resource management vignette had a preferred solution. Below we describe predominant themes expressed by panelists in discussion boards and text box comments. Themes were usually similar across panels. We indicate below the instances in which we identified thematic differences between AP and MP panels and highlight themes salient to within-panel uncertainty or consensus.

Thirty-nine panelists (17 MP; 22 AP), or 67% of panel participants, made a total of 786 rationale comments entered into text boxes (355 MP; 431 AP), an average of 39.3 comments per solution. Panelists commented in text boxes only in Round One. Most comments were brief, with an average word count of 22.33. Rationale comments totaled 17,548 words. On discussion boards, a total of 25 individual panelists (12 MP; 13 AP), or 43%, made a total of 78 discrete comments (33 MP; 45 AP) totaling 8371 words (average word count 107.32).

I. Dilemmas in Research Conduct

Both panels preferred to solve both research conduct dilemmas with a solution in which academic and community partners openly discussed and agreed upon issues related to study aims, data quality, and reporting of findings. The first vignette involved a conflict during development of a survey instrument that was determined to be scientifically valid but potentially too burdensome for the intended respondents. Panelists agreed on a solution that shortened the survey by choosing a smaller number of valid research constructs deemed most important to study aims. In preferring this solution, MP and AP panelists expressed a view of participatory research as concerned with dual goals of partnership and science. Of this solution, an AP panelist said it “seems like a compromise that is reasonable. Both partners were involved. Scientific integrity is maintained,” while an MP panelist said it “seems like a strong balance of scientific goals and community goals.”

Panelists expressed the importance of inclusive deliberation as a means to make research decisions. They wanted a process that would consider the implications of decisions for all members of the research team. As an AP panelist said, a research decision “should be a mutually beneficial decision that should involve all partners from the beginning of study design and throughout the research. Decisions shouldn’t be made that do not take into account how they impact all parties. While no one solution may meet everyone’s needs, that decision should never ignore anyone’s needs.” In deciding against a solution, one AP panelist said it “appeared unresponsive and somewhat disrespectful of the community partners’ concerns.” Another AP panelist found solutions to be “highly problematic” if they sounded like “academics ‘talking at’ vs. ‘solving with’ the partner.” Dismissing the solution in which a long survey was retained, an AP panelist said, “To me this solution is saying: ‘Nope, we need everything [in the survey], your input is not valuable. End of story.’” An MP panelist rated a solution as ethically appropriate because “Academics are listening to the community and [*sic*] to work with them,” while an AP panelist expressed “questions about the ethics of the original design” if it was developed without sufficient community input. Another AP panelist said a research dilemma “points to the need for extended periods of development ... and the inclusion of a broad spectrum of community ... so that issues like this don’t surface too far into the work.”

But most MP and AP panelists also indicated that, where dual goals of partnership and science came into conflict, scientific goals took precedence. Some expressions of this view were implicit, such as when an AP panelist said of a preferred solution that, “If the science remained strong, this is a very reasonable solution,” and an MP panelist said a solution that “seems like the strongest balance of science and community” would be appropriate “as long as done in a scientifically sound way.” Similarly, panelists did not prefer the option of developing a shortened survey for further validation. Of this solution, an AP panelist said it “was certainly ethical, but it doesn’t meet the needs of the researchers. And if it doesn’t meet researchers’ needs, then it can’t ultimately benefit the community. Efforts to be collaborative with a community should not override scientific integrity.” Another AP panelist similarly stated that the solution “helps community but not me as researcher so [*sic*] can’t then help community.”

A second vignette asked about the publication of null short-term findings. The vignette stated that, while short-term data showed no benefit from the intervention, community partners who had delivered the intervention and patients (*via* testimonials) had perceived benefits. AP and MP panelists objected to the solution to not publish short-term findings as “hiding null findings” (AP) and “ignor[ing] any obligation to publish the results of the short-term intervention,” (MP) even though publication could hinder community partners’ ability to provide the intervention since some agencies must demonstrate that their interventions are evidence-based. One MP panelist said that although findings may not be consistent with community preferences, “scientific validity should also play a role here.” Without dismissing the importance of consulting with community, an AP panelist said “ultimately, the investigator must use scientific judgment regarding all evidence, including the community’s perspective.”

In fact, central tenets of the scientific method – definitions of validity, reliability, and a responsibility to generate robust and objective findings – were described as commonly-held touchstones that could unite the research team. Panelists indicated that although those tenets themselves were not open to revision, deliberation within the partnership could promote understanding of scientific practice. Panelists expressed confidence that team members could agree on traditional methodological approaches if they were properly explained. As an AP panelist said, “It’s my experience that when people can see for themselves what the measures are and are invested in understanding the problem or issue themselves that [*sic*] a balance is struck between gold standard assessments and burden.” Another AP panelist described traditional methods as a source of unity: “In any research-community partnership that tests an intervention, all parties should agree that the purpose of the study is to determine whether the intervention is effective and that there is a possibility that the intervention will be found not to be effective.” In this model, the AP panelist continued, community involvement would be important “to interpret the results or to suggest new studies.” An MP panelist agreed that “the community understands that there the science is important and will defer to the researchers on this because they want to have a sound study also.” These panelists suggested that quality science produced consensus and dialogue – and *vice versa*.

Besides viewing tenets of scientific validity as an agreed-upon frame for the coalescence of the partnership, MP panelists in particular suggested that participatory approaches might improve science. An MP panelist argued in favor of engaging “the two sides in problem-solving” rather than ceding decision-making to researchers, which provides an “opportunity to work together and maybe even IMPROVE the instruments.” Another MP panelist argued that collecting patient testimonials could yield important results “if patient perceptions were part of the study design.” Another MP panelist suggested conducting a “pilot study to test assumptions of researchers and community members” regarding burdensomeness. An exchange on the AP panel emphasized a similar perspective of improving science without overturning established scientific approaches. Regarding publishing findings, an AP panelist asked, “If one considers science in general, whether astronomy, geology, biology or randomized trials, the publication and interpretation of results are based exclusively on the investigators experimentation and analysis. Should an exception be made for community-based research?” Another AP panelist responded that “[t]he data collected may impact or

change the community members' lives in a way that would not be the same in fields such as geology. The data should be examined in a manner that is meaningful to both the researcher and community participants...[because] the opportunity to interpret the data from the differing perspectives will help advance the science in new ways."

Three community stakeholders on the MP panel confronted what they perceived to be a pro-science bias in vignettes or comments. In an open text comment, an MP panelist from a community-based organization said a solution brought up the key issue of "which takes precedence – the scientific validity of a study or the participation of the community" and named as "one of the major issues in the field, the seemingly intransigent nature of scientific integrity." In discussion boards, another community stakeholder noted that other panelists were discussing "more impactful" results as synonymous with "scientific impact ranking, which limits 'impact that counts' to academic conversations." The panelist continued that "in real life, one might ask" about a range of potential impacts, and "couldn't it be the case that there are times that the 'most impactful' dissemination channel is one that focuses on the community rather than the scholarly audience?" This panelist identified the bias in the implied distinction between "important results," such as measurable outcomes "that the academics care about... and the 'other results' (i.e., the ones that matter to the community)." The panelist concluded with a "main point" that "the scenario and the question presume that the academic yardstick is the important one, which is actually a choice - not a self-evident truth." No other panelist responded to this comment. Elsewhere, a third MP panelist from the community sector argued for the inclusion of patient testimonials that conflicted with short-term results because "both researchers and patients participated in the study." The panelist continued that "[s]uch data is [sic] important enough to be included in the main body of the report. I personally think it is disrespectful to participants to treat their responses in this way" and suggested discussing within the paper how to deal with disparate results "when researchers and community disagree." This comment persuaded another MP panelist to revise ratings of the solutions: "I'm changing my vote – I think you're right." In sum, while most panelists indicated that the norms of scientific practice would not be revised through participation, a panel composed of mixed participants on occasion fielded objections that participatory projects should raise questions about the fundamental assumptions of those scientific practices.

II. Dilemmas in Resource Management

Panelists expressed less agreement regarding two resource management decisions than research decisions. No solution for the resource management vignettes was deemed appropriate, desirable and effective; but for both vignettes, solutions that offered resources to community stakeholders received highest ratings from both panels. In response to the first vignette, in which community members raised a concern about the need for higher study incentives, panelists gave highest ratings to a solution in which the extra funds were pulled from the academic budget. In the second vignette, rather than cease to collaborate with a community partner that was underperforming, the study increased the budget for the community partner and arranged for more training. Several panelists argued for the importance of community capacity building, like this AP panelist who said, "You have to be

committed to the community organizations and help them be successful.” In these ways, panelists sought equity, or the goal of giving all parties what they need to be successful.

Overall, panelists preferred that resources flow from academic to community stakeholders. This preference can be seen in comparing the most and least positively rated solutions to the first vignette about whether and how to pay study subjects. In the most positively rated solution, “the lead academic partner agreed to increase all participants’ incentives by \$10 from its own study budget.” In the least positively rated solution (inappropriate according to one panel and undesirable according to both) “the community partner that raised concerns about the incentive offered to increase all participants’ incentives by \$10 from its own operating budget.” Most panelists said that resources should be used to correct imbalances within the partnership. As an MP panelist said, “Generally speaking, the academic partner has access to a much broader range of resources.” Another MP panelist said that the resource management vignettes related to issues of “power-sharing ... including who is in the best position to absorb an additional cost” and rated solutions according to an assumption that “Generally, academia has much more leverage than community.” Like an AP panelist, many assumed academic partners could more easily extend resources: “does the community partner truly have the funds to double the amount?”

Panelists did not evaluate only relative resources but also the relative likelihood of benefit from a project. They described academics’ benefits as more secure. An MP panelist suggested that the research project as a whole was fundamentally if implicitly an activity driven by academic priorities: “Asking community agencies to absorb grant-related expenses doesn’t seem right to me. It doesn’t seem like just a matter of who has more to spend (though I agree this will pretty much always be the academic crew).” The panelist continued that, “the benefits to researchers that will result from the research getting done are generally much more secure (in terms of funding, pubs, etc.) and the risks less than for communities; and as such, [it] seems ok for academics to have more financial skin in the game.” An MP panelist understood the benefits of the project to favor an academic mission. For communities, “while in some cases there is some personal and professional benefits to being listed, e.g., as co-authors on papers, these are not central to the NPO struggle to serve and survive.”

As in research-decision vignettes, panelists expressed optimism that scientific validity and participatory processes were mutually reinforcing. For instance, an AP panelist described dialogue as a way to improve research quality: “Paying more to get a bigger sample could be coercive and inappropriate. Data from participants who join a study only for the incentive lack sufficient scientific quality to be meaningful. Open discussion of this issue is important for the team to make decisions that promote study validity.” Another AP panelist said, “I rated the first three solutions as more desirable than the fourth primarily because it states that solution was based on a discussion between academic and community partners. This dialogue is important. ALL partners should understand the advantages and disadvantages to each solution. Need to consider budget implications as well as impact to scientific integrity.” Another AP panelist agreed that “it is difficult to determine how best to balance scientific validity and maintaining trusting partnerships” but concluded that “one good principle would be for the team to conduct a deep dive as to what the problem is.” This may point the way to

“a viable solution to both maintain the partnership and also move the study forward.” In response to a question from a moderator about whether it is possible to have transparent discussions about finances as they impact validity, an MP panelist answered enthusiastically: “Yes! Shared power, shared unanticipated costs.”

Resource management vignettes particularly elicited panelist comments that decision-making required more details than vignettes provided. An MP panelist said the vignettes were “too generic to really make a judgment” and needed to know “the budgets/available monies of each organization and how much of a cost is being borne.” Another MP panelist said, “it isn’t clear [from the vignette] whether or not the weak partner could be supported in a way that would enhance their present and future capacity to participate in research partnerships.”

III. Dilemmas with Relationships

The final vignette addressed a scenario of interpersonal conflict on the research team. The scenario was taken from an interview with an academic PI who, in describing the steps pursued to resolve it, made a strong case that only one solution was ethical. In the scenario, a research assistant (RA) was perceived to have been disrespectful to a clinic staff member during a conflict over parking; in the real-world solution, the academic PI removed her from the project based on the preference of the community clinic director. However, when presented as a vignette, both panels agreed that this solution was inappropriate, undesirable, and ineffective. Instead, panelists preferred a solution in which the study PI accompanied the RA to the clinic to apologize and advocate for a special parking space for the RA. Neither panel rated any other solution as desirable, effective, or appropriate.

In explaining preferences, panelists did not cite aspects of the outcome, such as meeting the preference of the clinic director or allocating a resource to the RA. They discussed the decision-making process described in each solution, emphasizing conflict as an opportunity to strengthen the partnership. Commenting on the solution that removed the RA, an AP panelist said, “[p]roblems like this provide opportunities for learning and growth for all partners. If this solution is acted upon, then everyone loses and it is really not just the RA who is being unduly punished – the entire partnership will reap the consequences.” Panelists emphasized the opportunity for learning and practicing relational norms. An AP panelist said, “Removing the RA as a sacrifice to demonstrate deference to the study site doesn’t help anyone,” implying that a deliberative approach would yield benefits. Regarding the firing, another AP panelist said, “I believe that in the end no one has ‘learned’ from this solution.” An MP panelist echoed this sentiment: “it would be disrespectful for the researcher to roll over and bury the RA without an open discussion about what happened and what can be done to avoid similar situations in the future.”

Both MP and AP panelists described the academic PI as the individual responsible for preventing and managing the dilemma. An AP panelist thought about the leadership example set with each solution. She said, “If I were the PI in this situation, removing the RA would be disingenuous given that [the RA] meant no harm. That creates bad blood on the research team.” Panelists held the PI responsible for modeling a collaborative style. According to an AP panelist, “The PI, by virtue of being a PI, has been accepted as an ethical leader.” An MP

panelist said, “it is the PI’s responsibility to handle the situation.” Another MP panelist concurred that “it is not the job of the community partner to teach the staff; that is the job of the PI.” Another MP panelist agreed in principle with the idea of removing the RA but identified as more fundamental that a PI be an engaged leader: “I am ALL FOR erring, always, on the side of the researchers needing to bend to the community’s needs; but this solution feels like a kind of abdication of responsibility that actually undermines the long-term relationship.”

Indeed, panelists were scathing in their critique of the academic PI’s behavior as described in the solution that the real-life academic PI preferred. When asked if this solution could be acceptable, an AP panelist said bluntly, “No. This is unethical;” another AP panelist echoed, “Absolutely not.... I have significant concerns with it.” Another AP panelist agreed: “It is the responsibility of the PI to anticipate this kind of problem, educate the individual, and come up with a solution that becomes a learning opportunity for the research assistant.” An MP panelist said, “the PI should have prepared the RA and she never should have gone to the clinic alone for the first visit. She should have been introduced to the clinic staff, etc. It’s hard to imagine how this could happen if the PI were mindful and respectful of the partnership.” Another MP panelist said, “I actually want the PI to take some responsibility for sending this young woman off on her own[W]here is her mentor in this?!?” An AP panelist said succinctly, “ultimately I see the PI as the problem.” In these ways, panelists situated authority – for hiring, training, fostering ethics, and managing conflict – with the academic PI.

DISCUSSION

This study used vignettes describing common ethical dilemmas in participatory research to examine the potential ethical implications of adopting participatory approaches to conduct health research. When asked about possible solutions to ethical dilemmas, a diverse group of health researchers with varying degrees of experience conducting participatory research participating in our study attended closely to the interpersonal processes on the research team that underlie and facilitate knowledge production. This finding highlights the types of ethical considerations might become important in research projects using participatory approaches, highlight key questions for future research, and suggest options for education in participatory research ethics as participatory approaches become more frequently used.

Our findings provide empirical support for relationship-based ethics as a key concept in health research in the participatory era. Broadly speaking, in a relationship-based approach to ethics, aspects of relationships on a study team serve as guideposts for ethical decision-making. Drawing on case studies of community-based participatory research, Banks and colleagues define relationship-based ethics as “an approach to ethical questions focusing more on particular relationships and responsibilities” (Banks et al., 2013, p. 274) in contrast to principle-based ethics with its focus on individual rights and duties. The relationship-based approach prioritizes critical reflection on “positionality and power in the research process” and asks researchers to “constantly bear in mind the group dynamics of the research team, its inclusiveness, and barriers to participation” (Banks et al., 2013, p. 274). Banks and colleagues assert that “Whilst there are no easy answers or sets of rules that

provide definitive prescriptions for action, an awareness of the potential complexities and conflicts and a willingness and ability amongst research collaborators to reflect together on such issues throughout the planning and conduct” of research are important to research ethics (Banks et al., 2013, p. 274). Finally, Banks and colleagues emphasize the importance of researchers’ personal attributes, describing “ethics as embodied in researchers ... with a scope that includes the nature of relationships and qualities of character (such as trustworthiness and integrity)” (Banks et al., 2013, p. 275). Other scholars studying participatory teams have identified the importance to ethical decision-making of the relational climate on a study team – for example, the fostering of trust (Jagosh et al., 2015; Khodyakov et al., 2016) and respectful relationships (Shore et al., 2008) as well as norms of collaboration and power sharing (Mikesell, Bromley, & Khodyakov, 2013). While science studies scholars have long argued that interpersonal and emotional aspects of day-to-day science shape researchers’ ethical choices (Cohn, 2008; Pickersgill, 2012; Svendsen & Koch, 2008; Wainwright, Williams, Michael, Farsides, & Cribb, 2006), the wider adoption of participatory research approaches may heighten attention to the social and emotional work required for knowledge production.

Our data provide further insights on what the application of relationship-based ethics entails. While many of the studies cited above rely on case study methods, our study brought together a diverse group of researchers without a specific commitment to one research model or team and used vignettes to allow panelists to evaluate dilemmas one at a time. As a result, our findings identify ethical priorities that might be shared across project contexts. In response to vignettes, panelists with varying degrees of experience with participatory approaches delineated four features of a relationship-based approach to ethics. First, panelists indicated that ethical research decision-making should be inclusive of diverse perspectives. They agreed that it should result from an open discussion in which all stakeholders had sufficient input leading to agreement. They described their ideal preferred solutions as beneficial to all parties (“mutually beneficial”) but stated that no decision should ignore any stakeholders’ needs or disregard the implications of decisions for any research team member. More than once, panelists suggested dialogue should be respectful and, as such, they indicated that this dialogue in and of itself was important, including as a way to improve the overall quality of the research.

Second, panelists expressed preferences for solutions that advanced equity on the research team (Braveman, 2006), such as channeling resources to those with less and extending protections to those with relative vulnerabilities. For instance, a panelist indicated that a research team should be committed to helping partnered organizations be successful. They endorsed decision-making processes that explored who would be in a position to absorb extra costs and defined this flow of resources from one stakeholder to another as a type of power sharing. Panelists’ approach reflects Mooney’s definition of vertical equity in which different needs require different resources such that more resources are allocated to those with greater need (Mooney, 1983).

Third, panelists understood relationships – even if sometimes conflictual – as resources for the research team. For instance, they described relationship-building as a means to foster trust that could facilitate collaborative decision-making. Panelists never preferred the

solution we constructed to be a temporary solution that muffled conflict, suggesting that they recognized and declined solutions that closed debate. Instead, several panelists described conflict as an opportunity for team growth. Problems or conflicts were seen as opportunities to strengthen the collaboration, and panelists highly valued learning and growing through relationships on the team (e.g., by learning about others' perspectives). Panelists suggested that ethical dilemmas can be a way to deepen and then utilize the relational context to move forward on scientific goals. That is, panelists perceived that efforts to work together to define and implement ethical practice simultaneously supported the team's cohesion around other tasks, particularly scientific ones.

Panelists described a fourth feature of relationship-based ethics: placement of the *processes* leading to decision-making (e.g., as respectful, responsive, and inclusive) at the center of a definition of ethical research practice. While weighing solutions, panelists emphasized processes like recognizing stakeholders' different views, foregrounding possible implications, and constructing shared goals as the ethical underpinnings of decisions of all types. Even regarding some choices described as non-negotiable (e.g., definitions of scientific validity), panelists sought to reach solutions only after inclusive discussion. This process orientation reflects what we have referred to elsewhere as the priority of embodying ethical action whereby researchers perceive ethics to be made manifest not in compliance with protocols or policies but through ongoing attention to ethical implications [author reference]. Our data suggest that relationship-based ethics – with its features of responsiveness to diverse perspectives, support for vulnerable team members, consideration of relationships as resources, and prioritization of process – may have relevance for researchers adopting participatory approaches.

Best Practices

Panelists' endorsement of relationship-based ethical approaches suggest that they may draw best practices from normative ethical frameworks that are broader than those underlying current research ethics guidance and policy (e.g., the Belmont Report and Department of Health and Human Services policies including 45CFR26). For instance, panelists' perspectives are consistent with a goal of achieving *procedural justice* in which marginalized groups "gain a seat at the table—and stay at the table, having a real voice in decision making affecting their lives" (Minkler, 2010) (p. S81). Ensuring procedural justice means that all individuals have the right to be given equal concern and respect in decision-making. Procedural justice can be achieved by practicing inclusiveness and fair representation, parity, and open communication. Similarly, panelists' views are consistent with some aspects of Goering and colleagues' model of *responsive justice* (Goering, Holland, & Fryer-Edwards, 2008). Responsive justice includes the principles of (re)distribution by which goods and services are distributed in ways that first meet the needs of underserved or marginalized groups and then aim to equalize opportunity. Responsive justice also includes the principle of recognition in which researchers establish "a reciprocal relation of respectful engagement and attentive concern" with one another to facilitate power sharing and ensure that no individuals or groups "are ignored, unfairly (if unintentionally) stereotyped, categorized as inferior, denied a voice in decision-making, or undervalued or marginalized as participants" (Goering et al., 2008, p. 46). Responsive justice is "interactive and dynamic" in its

implementation and requires vigilance throughout a project (Goering et al., 2008, p. 51). Best practices derived from normative frameworks like procedural justice and responsive justice may gain relevance through broader adoption of participatory approaches.

Research Agenda

Our findings raise questions about scientific leadership and relationship-based ethics that warrant further study. More research is needed to understand the contexts in which relationship-based ethical priorities are adopted by teams. For instance, research could explore the extent to which researchers adopt relationship-based ethical approaches on research teams that have limited roles for non-scientists (e.g., patient representatives on an Advisory Panel) and on teams with different stakeholder compositions (e.g., representatives of groups with historical disadvantage or power imbalances). Further studies could also describe conflicts between scientific and relationship-based values. For instance, panelists described inclusive dialogue, seeking fairness, and other relational processes as key to the resolution of ethical dilemmas as long as these processes did not challenge accepted tenets of scientific validity. Panelists understood the scientific method (e.g., measure validation) to be a framework around which participants could coalesce. Panelists described as an ideal that scientific and partnership goals could be “balanced,” or they expressed a belief that partnership activities (e.g., dialogue) would promote understanding of or improve science. Yet panelists did not describe scientific methods as available for new types of agreements. Solutions that implied the legitimacy of alternate types of knowledge – such as a community-authored survey – were not preferred. Overall, panelists expected to make trade-offs when working with non-scientist stakeholders, but they did not endorse tradeoffs that would undermine or reconceptualize scientific validity. One illustration of panelists’ retention of traditional assumptions about scientific practice was their embrace of the leadership of the academic PI: that a single scientific leader should direct activities, model team culture, and act as an ethical guide. However, this finding may reflect the fact that the vignette itself gave an active role to the academic PI. Notably, the resource management vignettes, neither of which foregrounded issues of scientific validity or scientific leadership, elicited the most uncertainty from both panels.

Our findings suggest that many panelists recognized the interactions on the research team to be value-laden and therefore open for ethical deliberation but perceived the scientific method to be value-free. Panelists perceived that negotiation required taking another’s perspective but may have perceived the scientific process to rest on objective procedures. Panelists may have viewed participatory processes as a means to integrate value-laden relational concerns and value-free scientific norms. Perceived as neutral, panelists assumed that participatory approaches would reinforce rather than undermine them. Yet community-based members of the MP panel – the panel whose composition was most like a partnered research team – did object to pro-science biases. That these objections generated little debate may suggest that the “seemingly intransigent nature of scientific integrity,” as an MP panelist said, may cause latent tensions on real-life teams. Despite evidence of increasing adoption of participatory research approaches, our findings and others’ (Cook, Kesby, Fazey, & Spray, 2013) suggest that unacknowledged assumptions could limit who is brought to the table, what can be openly discussed, and whose ideas are influential. Participatory research approaches could

change who works on a research team while leaving intact extant scientific norms and leadership. This dynamic warrants further study, particularly as participatory research approaches are promoted to increase public trust in science, ensure science is accountable to constituents' needs, and provide specific protections to historically disadvantaged groups (Beaton et al., 2016).

The study has several limitations that could be addressed in follow on studies. Our findings are limited by variable rates of panelist comment (67%) and missing data from 5 participants who completed task 1 but not the vignette task. Vignettes may have introduced bias. As stated in the introduction, we sought to design vignettes that elicited views on conflicts between scientific and participatory aims and for relationship-based themes. Vignettes may have included clues that these were the topics of interest, such as descriptions of relationship conflicts and questions about standards of scientific validity. Moreover, resource management dilemmas gave panelists solutions to redistribute resources in ways that corrected imbalances. In all cases, we attempted to minimize bias by providing an array of solutions, reviewing vignettes during development with different stakeholders, and ensuring that vignettes did not inadvertently imply a preferred solution. Our sampling strategy also had limitations. The purposive, maximally variant sampling approach yielded a majority of academic panelists and underrepresented community stakeholders' views, but this panel composition captured current norms within research institutions. We did not gather detailed information about panelists' level of experience with participatory research approaches. We did so with the intent of broadening participation and discouraging panelists from referencing a prior research experience rather than confronting vignettes directly. Moreover, we understood our sample size would be too small to analyze relationships between degree of participatory experience and panel responses. However, this choice limits our ability to examine how past participatory research experiences shaped panelists' views. Such information would be best gathered using a more homogeneous sample and structured assessments of ethical priorities and experiences with participatory projects (Khodyakov et al., 2012). In addition, particularly in response to resource management dilemmas, panelists said that vignettes did not model all of the variables a team would take into account in determining an ethical course of action. Vignettes implied but could not fully describe the relational processes used to reach solutions, and these were key to decision-making. Finally, since findings are not based on direct observation, we cannot know whether panelists' responses reflect everyday practices or their recognition of ethical norms.

Educational Implications

Regardless of these limitations, this study provides guidance in training researchers in the responsible conduct of research in the participatory era. Our study is innovative in its use of vignettes and the online modified-Delphi method to query the attitudes that shape ethical decision-making. It posed complex dilemmas, four viable solutions, and generated sophisticated dialogue. Findings suggest vignettes could be effective teaching resources. For instance, the Community Partnered Research Ethics Training (CPRET) program developed at the University of Pittsburgh engages academic and community partners to develop scenarios of desirable and less desirable research situations that allow them to articulate ethical priorities and examine conflicts (Yonas et al., 2016). Although we included a diverse

group of researchers, their responses demonstrated high consistency quantitatively (e.g., that three of five vignettes had preferred solutions across two different panels) and qualitatively (e.g., a common theme of emphasizing decision-making process), suggesting diverse teams can work through dilemmas to reach common conclusions about ethical choices. Further, findings suggest that participatory research ethics may not be teachable as a set of principles (Petersen, 2013). Panelists were reluctant to define principles that should guide ethical research in any context, qualifying most comments (e.g., “Generally, academia has much more leverage than community”) to suggest they may not always apply. Similarly, teaching tools that focus on the outcome of an ethical dilemma or the standards that should be met may not be sufficient (Stellefson et al., 2015), as suggested by the fact that panelists opposed a solution that a real-life PI had forwarded as the only ethical solution. Instead, panelists often preferred solutions that suggested a certain kind of decision-making process (e.g., inclusion of all perspectives, responsibility is not abdicated). Like the CPRET model, vignette-based teaching strategies that can elicit debate between diverse stakeholders about how decision-making can embody ethical action might be most appropriate for teaching participatory research ethics.

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Research Dilemma: Long Survey

Agreement: [COMPROMISE]

Appropriate, but of uncertain desirability and effectiveness: [CONFLICT AVOIDANCE/TEMPORARY SOLUTION]

A team of academic investigators working on a study about the health of homeless individuals drafted a survey protocol and shared it with their community partners. The study sample is 1,000 people. The protocol consisted of previously validated scales which all measure different constructs important to the study. Academics estimated that it would take an average respondent 60 minutes to complete this survey. Upon review, community partners felt that a 60-minute survey was too long for respondents and suggested cutting it in half.

Solutions

1. Academic partners explained that the previously validated scales should not be altered and that, for the purpose of ensuring scientific integrity of the study findings, all questions should be retained. **[PRO-ACADEMIC]**
2. Academic and community partners agreed to remove half of the items from each scale to shorten the survey. The team agreed to take the time to validate the new instrument. **[PRO-COMMUNITY]**
3. Academic and community partners discussed how each construct measured with the survey is related to study aims. After prioritizing constructs, they removed the scales that they agreed were the least relevant to study aims. **[COMPROMISE]**
4. A study team agreed to keep the survey instrument intact, but decided to allow participants to complete the survey in two sittings. **[CONFLICT AVOIDANCE/TEMPORARY SOLUTION]**

Research Dilemma: Publication

Agreement: [COMPROMISE]

A team of academic and community partners collaborated on an NIMH-funded study about depression care that evaluated the effectiveness of a brand new clinical intervention. The study was designed to measure short and long-term intervention impact. Short-term outcome data was collected at the end of the intervention and long-term outcome data would be collected 12 months later. The short-term outcome data suggested that the intervention was not effective. However, community partners, who delivered the clinical intervention, cited numerous participant testimonials and real life stories of intervention benefits to patients and their family members. Community partners said that their patients liked the new treatment and wanted to continue receiving it. Clinicians worried that publishing null findings would jeopardize their ability to offer this treatment and might negatively affect their relationships with patients.

Solutions

1. Partners agreed to publish two articles in the same issue of a new “online only” peer-reviewed journal. The first article presented short-term outcome data, indicating that the intervention was not effective. The second article used testimonials to illustrate how the intervention helped participants. **[CONFLICT AVOIDANCE/TEMPORARY SOLUTION]**
2. Partners agreed not to publish the short-term outcome data and to wait until long-term data were available. They published a paper using patient testimonials and real life stories to illustrate the positive impact of the intervention from the patient perspective. **[PRO-COMMUNITY]**
3. Academic partners reviewed and explained all data analytic steps to their community collaborators. All team members recognized their obligation to publish study findings. They proceeded to publish short-term outcome data showing no effect. The discussion section of the article, however, acknowledged positive patient testimonials. **[COMPROMISE]**
4. Partners agreed not to publish any articles until the long-term data were available. **[PRO-ACADEMIC]**

Resource Management Dilemma: Survey Incentives

Appropriate, but differences on desirability and effectiveness: [PRO-COMMUNITY]

A team of academic investigators working on a study about the health of homeless individuals drafted a survey protocol and shared it with their community partners. The study sample is 1,000 people. Academics estimated that it would take an average respondent 60 minutes to complete this survey. The lead community partners' budget included participant incentives in the amount of \$10 per completed survey, which was above local minimum wage rates. One of the community partners representing a small clinic voiced concerns that the \$10 incentive was not sufficient to ensure high participation rates.

Solutions

1. After discussions between all academic and community partners, the lead community partner agreed to increase all participants' incentives by \$10 from its own study budget. [PRO-ACADEMIC]
2. After discussions between all academic and community partners, the lead academic partner agreed to increase all participants' incentives by \$10 from its own study budget. [PRO-COMMUNITY]
3. After discussions between all academic and community partners, all partners agreed that no additional incentives could be offered to participants due to budget constraints. [COMPROMISE]
4. The community partner that raised concerns about the incentive offered to increase all participants' incentives by \$10 from its own operating budget, and the team accepted this offer. [CONFLICT AVOIDANCE/TEMPORARY SOLUTION]

Resource Management Dilemma: New Partner

Appropriate and effective, but differences on desirability: [PRO-COMMUNITY]

Several universities and community partner agencies were participating in a high-profile CBPR study about public health effects of soil pollution. One of the community agencies, Agency X, was new to the partnership, but came highly recommended by a trusted community partner, Agency Y. Agency Y was not only involved in many of your previous CBPR projects, but was also active in the current project. During early data collection, several academic and community project participants were noticing that Agency X was far behind on its tasks, which could have jeopardized the success of the whole project. Simultaneously, another community agency, Agency Z, approached the project leadership with an interest in joining the study. To some, Agency Z seemed to be a perfect candidate to take over the responsibilities of Agency X. In partnership meetings, the director of Agency Y defended Agency X, saying that Agency X needed time to get used to the demands of research tasks. There was no budget to bring Agency Z on board without changing the original budget allocations to existing study partners.

Solutions

1. After a long discussion, Agency Y agreed to reduce its budget by 50% so that both Agency X and Agency Z could work on the project. **[PRO-ACADEMIC]**
2. After a long discussion, partners agreed to reduce Agency X's scope of work and re-allocate the study budget so that Agency Z could be hired immediately in an attempt to safeguard the project's success. **[COMPROMISE]**
3. All academic and community partners agreed to enhance the research capacity of Agency X by offering more training to its personnel and redirecting 2% of the study budget to this agency. Agency Z was not hired. **[PRO-COMMUNITY]**
4. Although Agency Y disagreed with this decision, project leadership replaced Agency X with Agency Z to safeguard the project's success. **[CONFLICT AVOIDANCE/TEMPORARY SOLUTION]**

Relationship Dilemma: Research Assistant

Agreement: [PRO-ACADEMIC]

A recently-hired undergraduate research assistant went to one of the community partner clinics located in an unfamiliar neighborhood to collect data. Out of concern for her own safety, she parked her new car in a vacant parking spot right by the front entrance of the clinic. As she left her car, a man stationed at the entrance approached her and told her that the spot was reserved for elderly patients. The research assistant explained that she was a researcher coming to the clinic to collect data for the partnered study, that the parking spot was vacant, and that there was no signage that the parking spot was reserved. Unbeknownst to her, the man was a security guard at the clinic. He reported the situation to the clinic director who considered the research assistant's behavior disrespectful and immediately notified the study principal investigator at the university saying that this person should no longer come to the clinic site.

Solutions

1. In response to this incident, all academic and community partners were required to attend a meeting where an external relationship consultant helped them develop a study-wide approach to handling difficult interpersonal situations. **[CONFLICT AVOIDANCE/TEMPORARY SOLUTION]**
2. The academic principal investigator notified the IRB about this incident and decided to remove the research assistant from the project because the clinic director considered her behavior disrespectful and did not want to see the research assistant on the clinic site in the future. **[PRO-COMMUNITY]**
3. Upon hearing the research assistant's story, the academic PI went to the clinic with the research assistant to apologize for the misunderstanding with the security guard. The PI and the clinic director agreed to reserve a parking spot close to the clinic entrance for research team members during the data collection stage of the study. **[PRO-ACADEMIC]**
4. Community partners educated the research assistant about the importance of respect and building relationships with study partners. The research assistant underwent a cultural sensitivity training module and was reassigned to another study data collection site. **[COMPROMISE]**

Table 1

Demographic and Professional Characteristics of Study Participants (%)

Demographic and Professional Characteristics	Academic Panel (n=33)	Mixed Panel (n=30)	P value for difference in means	Combined Sample (n=63)
Gender				
Male	27.3	30.0	0.811	28.6
Female	72.7	70.0		71.4
Race				
White	81.8	86.7	0.729	84.1
Black	6.1	6.7		6.4
Asian	6.1	0.0		3.2
Other	6.1	6.7		6.4
Hispanic				
Yes	9.1	16.7	0.462	12.7
Degree				
Bachelor's degree	3.0	10.0	0.753	6.4
Master's degree	9.1	3.3		6.4
Professional degree	9.1	6.7		7.9
Doctorate degree (PhD)	54.6	56.7		55.6
Professional (MD) and doctorate degree (PhD)	24.2	23.3		23.8
CEnR Experience				
Yes	100.0	80.0	0.009	90.5
No	0.0	20.0		9.5
Research Type*				
Pre-clinical/bench research	0	6.7	0.654	3.2
Treatment/intervention discovery & development	30.3	30		30.2
Health services/implementation research	27.3	16.7		22.2
Population health research	42.4	46.7		44.4
Group				
Researchers	100.0	63.3	<0.001	82.5
Community members	0.0	23.3		11.1
Other	0.0	13.3		6.4
Organization				
University	75.8	56.7	0.013	66.7
Community-based organization	0.0	16.7		7.9
Healthcare services agency/organization	0.0	10.0		4.8
Other (e.g., non-profit research institution)	24.2	16.7		20.6

Notes:

* Participants were asked the following question: "Which statement best describes the type of research you typically conduct or are most familiar with?" (1) Pre-clinical or "bench" research directed at mechanisms and presentations of human disease [Pre-clinical/bench research]; (2) Testing

basic science discoveries for clinical effect and/or applicability [Basic science discovery]; (3) Testing new interventions in human subjects under controlled environments to form the basis for clinical applications and evidence-based guidelines [Treatment/intervention discovery & development]; (4) Research on the application of new interventions or therapies in general practice. Research that yields knowledge on best ways to implement new medical interventions in the clinic [Health services/implementation research]; (5) Investigations of factors and/or interventions that influence the health of populations; research that ultimately results in improved health of the public [Population health research]

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Table 2

Panel Decisions Based on the RAND/UCLA Appropriateness Method

Solution	Academic Panel				Mixed Panel			
	APP	DES	EFF	APP	DES	EFF	APP	EFF
<i>Research Dilemma: Whether & How to Shorten Long Survey</i>								
Retain all scales	-(2)	-(1)	-(1)	±(4)	-(2)	-(1)		
Cut in half & validate	±(5)	-(3)	-(3)	±(6)	±(5)	±(6)		
Retain some validated scales	+(9)	+(8)	+(9)	+(8)	+(8)	+(8)		
Complete in two sittings	+(6.5)	±(5)	±(5)	+(7)	±(5)	±(6)		
<i>Research Dilemma: Whether to Publish Short-Term Null Findings or Positive Patient Testimonials</i>								
Await long-term findings	±(4)	-(3)	±(3.5)	±(5)	±(5)	±(5)		
Publish patient testimonials	-(3)	-(1.5)	-(2)	-(3)	-(2)	-(3)		
Publish null findings	+(8)	+(8)	+(7)	+(7)	+(7)	+(7)		
Publish both online only	±(5)	-(3)	±(4)	±(5)	-(2)	-(3)		
<i>Resource Dilemma: Whether to Increase Survey Incentives & From Which Budget</i>								
Community budget	±(5)	±(5)	±(5)	±(5)	±(5)	±(5)		
Academic budget	+(6.5)	±(6)	±(5)	+(7)	+(7)	+(7)		
No increase	+(7)	±(5)	±(5)	±(5)	±(5)	±(5)		
Single agency budget	-(3)	-(3)	±(4)	-(3)	-(3)	±(4)		
<i>Resource Dilemma: Whether to Replace or Support New Partner Struggling with Responsibilities</i>								
Agree to replace partner	±(4)	-(3)	±(4)	±(4)	-(3)	±(4)		
Support & train partner	+(7)	±(6)	+(7)	+(7)	±(6)	+(7)		
Reduce partner tasks	±(5)	±(5)	±(5)	±(6)	±(5)	±(5)		
Replace partner despite opposition	-(2)	-(1)	-(2)	-(2.5)	-(2)	-(2)		
<i>Relationship Dilemma: By Taking Parking Spot, RA Oversteps & Community Partner Feels Disrespected</i>								
PI apologizes, arranges parking	+(7)	+(7)	+(8)	+(8)	+(8)	+(8)		
Remove RA from entire project	-(1.5)	-(1)	-(1.5)	-(1)	-(1)	-(1)		

Solution	Academic Panel			Mixed Panel		
	APP	DES	EFF	APP	DES	EFF
	Research Dilemma: Whether & How to Shorten Long Survey					
Educate & reassign RA within project	±(4)	±(4)	±(4.5)	±(5)	±(3.5)	±(5)
Bring in relationship consultant	±(5)	−(2)	−(3)	±(5)	−(2)	±(4)

¹ APP=appropriateness; DES=desirability; EFF=effectiveness

² + Positive decision: panelists considered a given solution appropriate, desirable, or effective.

³ ± Uncertain decision without disagreement: panelists were uncertain about the appropriateness, desirability, or effectiveness of a given solution.

⁴ − Negative decision: panelists considered a given solution inappropriate, undesirable, or ineffective.

⁵ Numbers in parentheses: Median value, range 1–9.

⁶ Shaded rows: Preferred solution that both panels considered appropriate, desirable, and effective.