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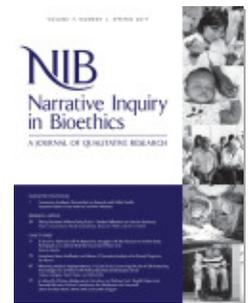
## Introduction: Community–Academic Partnerships in Research and Public Health

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Narrative Inquiry in Bioethics, Volume 7, Number 1, Spring 2017, pp. 1-4  
(Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/nib.2017.0001>



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## Introduction

# Community–Academic Partnerships in Research and Public Health

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**Conflicts of Interest.** The authors report no conflicts of interest.

**Abstract.** This symposium includes twelve personal narratives from individuals and teams who have been engaged in community–academic partnerships in research and public health. This issue also includes four commentaries on these narratives by experts in patient and research subject advocacy, healthcare and biomedical ethics, social science, and health education funding. While much has been written about community–academic partnerships, what appears in the literature does not include in–depth, personal reflection on the challenges and obstacles faced in these partnerships. With this symposium, we aim to stimulate reflection and discussion about creative approaches to community–academic partnerships in order to guide those who are both new to and experienced in community–engaged work.

**Key Words.** Bioethics, Academic Engagement, Bidirectional Partnership, Partnered Research, Stakeholder Engagement, Community Partners, Patient Engagement, Community Engagement, Health Disparities

## Background

Academics have been partnering with communities for decades (Israel, Schulz, Parker, & Becker, 1998). Community engagement is touted not only as the “more ethical” thing to do, but often the “more practical” thing to do in health–related research and service delivery (Wallerstein & Duran, 2008). This practicality recognizes the breadth of the knowledge base that informs research and values collaboration among academic professions in association with community partners. The idea that conducting research or delivering programs *with* community

partners—as opposed to *on* them or *to* them—would increase participation and relevance certainly makes logical sense. Yet, community engagement is still not widely practiced, embraced, or rewarded in academia (Calleson, Jordan, & Seifer, 2005), nor are its ideals easily met by those who attempt, with all the best intentions, to do it right.

Why not? The short, perhaps too glib answer is that community engagement is hard work that is anything but straightforward. It is also somewhat mysterious and intimidating to those who have not attempted it. Meeting the ideals of true partnership

cannot be achieved by simply following a series of pre-determined steps. There is no clear recipe to follow. Community engagement is an approach—a mindset, rather than a method *per se*. Different groups have proposed guiding principles for community engagement (for example, see Clinical and Translational Science Awards Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011). While these principles are useful in communicating the general ethos of community engagement, like other codes of ethics and professionalism, they do not provide specific guidance for how to act in specific, complex situations. Certainly experience helps, but every community and every project are different and the localness of projects within each community differentiates the level of engagement.

Published reports of the results of scientific experiments usually present an overly polished version of what actually happened; false starts, wrong turns, and flat out failures are absent, and the final product presents a streamlined, hassle-free version of the truth (Grinnell, 2009). The same might be said about published reports of the results of community-engaged research (although the journal *Progress in Community Health Partnerships*, which is devoted entirely to community engagement, does have special sections featuring lessons learned and community perspectives). Community and academic partners often do not have luxury of space in which to reflect on challenges and obstacles so that others might learn from them. Learning the lessons of other partnerships, even those that suffer from breakdown, can potentially promote (or renew) the sense that collaborative relationships offer opportunities for parties that neither could achieve in isolation from each other.

Anecdotally, we know that almost everyone who has engaged in community-academic partnerships—on both sides of the equation—has stories of the “you just can’t make this stuff up” variety. Often, the biggest challenges were not and likely could not have been anticipated. Challenges still would have arisen despite parties’ familiarity with best practices, dedication to cultural humility, and adherence to proper process. We also know that

community-academic partnerships in public health can profoundly change people. For researchers, more than their career trajectory can be affected. For communities, the impact extends beyond health improvement.

In this special symposium, we asked academic researchers, service providers, and leaders of community organizations who have actively engaged in community-academic partnerships to share their personal stories. We wanted to hear about how they have been personally affected by these partnerships—with the study aims, methods, and findings taking a backseat to their own experience and reflection on challenges, obstacles, and lessons learned. What we aimed to achieve was a collection of thought-provoking dilemmas and words of wisdom that perhaps demystifies the processes associated with engagement for others planning or in the middle of community-academic partnerships.

### The Call for Stories

In the call for stories, we sought submissions from individuals with first-hand experience engaging in community-academic partnerships to conduct research or deliver health care or public health services. The call was open to academic researchers, service providers, and leaders of community organizations. We were interested in the exploration of partnership challenges, strengths, and lessons learned from a personal perspective. We wanted authors to share the types of experiences that often get left out of academic publications.

Authors were asked to consider the following questions:

- What kind of research or service project did you conduct?
- What roles were played by community partners? What roles were played by academic partners?
- How did each of the partners contribute to shaping the project’s goals, approach, and outcomes?
- What was positive about the partnership experience?
- What obstacles or challenges did you face in the partnership?
- What do you wish you had known before establishing the partnership?

The call for stories was included in the NIB newsletter and on the NIB website. Additionally, the call was posted on social media platforms and sent directly to colleagues known to be active in community engagement and networked with others doing similar work. The call was also distributed on several listservs managed by Community Campus Partnerships for Health (CCPH) (<https://ccph.memberclicks.net/>). We were very pleased by the response to the call for stories, and received 35 proposals despite having a lead time of only six weeks.

### The Narratives

The 12 stories that we included in this issue reveal a variety of experiences. The large number of proposals allowed us to include narratives representing a very diverse group of community–academic partnerships as well as a diverse group of authors. We heard from a broad range of academics from the health and social sciences and service providers working with communities across the country: *promotores* in East Los Angeles; an Amish community; Congolese refugees in Indianapolis; a transgender health program in Portland, Oregon; a community health center in Minneapolis; a practice–based research network focusing on Hispanic health in Charlotte, North Carolina; Afghan immigrants in Northern California; African–American women in Milwaukee; a diverse group of community research advisors in Madison, Wisconsin; people living with HIV; media outlets in rural American Indian and Alaska Native communities; elders in rural South Carolina.

While it is not surprising that the majority of partnerships at the center of the narratives involve research, a few stories also come from community–academic partnerships centered on the delivery of health services or educational programs for future health care providers. While some academics submitted their own personal narratives, others wrote collective stories, discussing events from multiple perspectives. Several authors wrote about their experiences as graduate students. Topics covered

include the health care experience, including care at the end–of–life; dual roles, conflicts of interest, and challenges to privacy and confidentiality; cultural differences and cultural competence; shared ownership of projects; the importance of trust, flexibility, humility, and openness; experiences of discrimination and stigma; and social determinants of health. The stories, locations and those impacted vary and yet the collective experiences, challenges and struggles to move a research partnership towards sustainability followed similar threads.

Because of the large number and diversity of submissions, six additional stories are also included in the online supplement for this issue.

### The Commentaries

This symposium includes four expert commentaries on the narratives, which draw out themes and lessons learned. These commentary authors are experts in patient and research subject advocacy, healthcare and biomedical ethics, social science, and health education funding. Ms. Gianna McMillan is a patient and research subject advocate who specializes in consent issues in clinical trials; the rights of children and their families in research; and the collection of oral histories of research and bioethics. Dr. BJ Crigger is the director of Ethics Policy for the AMA. Dr. Crigger is an expert in bioethics and advocates for the use of narratives to teach students about major bioethical issues. Rebecca Dresser is an expert in biomedical ethics. Since 1982 she has taught law and medical students about legal and ethical issues such as end–of–life care, biomedical research, genetics, and assisted reproduction. She has written extensively about research subjects and patient advocates and the important roles they can play in promoting ethical research. Dr. Nina Tumosa is a leader in geriatrics education and research. Her many years of service in the Federal Government includes fifteen years with the Veteran’s Administration and at present, as a Public Health Analyst for the Health Resources and Services Administration, U.S. Department of Health and Human Services.

## Conclusion

Our primary goal with this symposium was to provide a platform for individuals engaged in community–academic partnerships to reflect on some of the more nuanced challenges of such work, as well as the ways in which they themselves had been personally affected by the partnership. The human stories of partnerships inevitably develop as teams meet, set specific aims and deadlines, complete project milestones, and write reports. Yet the human side of community–academic partnerships gets no more than a few lines in an academic publication—while human lives are profoundly affected. The fact that we received so many story proposals suggests that individuals engaged in community–academic partnerships have so much more to share than what is published in the traditional academic literature.

A list of references for publications that report findings from studies conducted by the community–academic partnerships detailed in the symposium in this issue are listed on the NIB website at <http://www.nibjournal.org/current/index.html>.

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## Personal Narratives

### Two Steps Forward, One Step Back: Dancing Toward Equitable Collaboration

Rosana Leos Bravo, Angela Gutierrez,  
and Maria–Elena De Trinidad Young

Alma’s flustered voice burst out, “¡Pues, ya díganos! ¿Qué quieren que hagamos?” The outcry startled and confused us, breaking our attention and pulling us away from our facilitation notes—pages replete with our detailed plans for the meeting. It was a Friday evening after each of us had completed a full workday and fought the Los Angeles traffic. We were exhausted, to say the least. Furthermore, our meeting was taking place under time constraints because the East Los Angeles community center where we met was closing in an hour.

The members of our group—six *promotoras*—were antsy to move our collaborative project along. So were we. We were doggedly making our way through our plans to elicit discussion from the group to hone in the focus and objectives of the *promotoras*’ project. We were in our fourth meeting and had already spent the first hour attempting to lead a participatory decision-making process by asking the group our carefully crafted open-ended questions about their strengths and needs. The *promotoras*, who had formed a grassroots collective, had reached out to us in their efforts to develop the skills to initiate their own health promotion projects. On that hot, summer evening they had been politely, if somewhat listlessly, responding to our questions: What skills do you currently use? What skills would you like to gain? What types of research questions would you like to explore?

Alma’s words, “Okay, just tell us what you want us to do already!” marked the moment when we realized that our orchestrated recipe of participatory group processes was not helping us build a relationship with our community partners. It was not serving to move us towards an open exchange of ideas for the project. Alma pushing her chair away from the table where the nine of us were