

# Narrative 15

## Voices of Experience

Laura Weiss Roberts

We asked academic faculty colleagues who work closely with community partners to comment on aspects of their collaborations. We explored how partnerships are important and how to best approach partnerships. We asked about the strengths and barriers in collaboration. We also inquired about what academic faculty colleagues wished they had known at the beginning of their collaborative work. What follows are some “pearls of wisdom” from their lived experiences in partnerships.

### **Question: Can You Say a Bit About Why Community-Academic Partnerships Are Important to You and to Your Work?**

Community-academic partnerships can address questions that uniquely impact community members. Each partner brings specific expertise and skills that are necessary in developing approaches and interventions to solve complicated biomedical and psychosocial problems in a manner that is culturally appropriate and sensitive.

Cheryl Gore-Felton, Ph.D.

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As those in academia learn from and respect the intrinsic knowledge, voice, and experience of those in the community, the strengths of all are brought together to create elegant solutions.

Steven Adelsheim, M.D.

Community-academic partnerships ground academicians to the real world and open the community to the struggles of research.

Michele Barry, M.D.

In order for academic work (e.g., research, program development) to create impact, the work needs to be significant, feasible, and sustainable. Community-academic partnerships engage stakeholders in this process. This relationship safeguards that these components are addressed during design, implementation, and evaluation of an intervention or program.

Victor G. Carrion, M.D.

Growing up in a Christian church, I was taught that “faith without works is dead.” In my university career, I have learned that “scholarship without service is dead.” Mental health is not physics: We are rarely discovering how an electron works or some other bit of basic knowledge. Instead, we strive to acquire knowledge in the service of society. That by definition means engaging society at all levels.

Keith Humphreys, Ph.D.

Research and academic training that are not rooted in community needs, values, and priorities are doomed to failure. Transcendent collaborations that uniquely synthesize scientific and programmatic expertise increase the likelihood of developing an intervention or program that is scientifically efficacious, programmatically valid, and responsive to community needs, values, and priorities.

David Wyatt Seal, Ph.D.

It is important to me because the university setting is often full of researchers and clinicians who want to help the community and who may have burning questions for which the community may have some answers (and more questions). Hence, a dialogue can start, and a mutually beneficial relationship can be created and sustained. Also, I think it’s particularly salient when you live in the community where you work...you become part of the landscape and the research questions become more natural and obvious.

Shashank V. Joshi, M.D.

Academic endeavors must ultimately provide some benefit, whether direct or indirect, to the general population and, sometimes, to specific communities. Partnering with these communities will enrich the nature of the academic inquiry and lead to more robust applications.

Yvonne Aida Maldonado, M.D.

I have had a rewarding, synergistic experience between my professional work—in which I try to serve my profession in its desire to provide greater understanding and better treatment of the mental health needs of LGBT patients—while serving my gay community as an occasional spokesperson to the wider world in support of their civil rights, health, and mental health needs.

Jack Drescher, M.D.

As a vice chairman for education and director of a forensic psychiatry fellowship, I tremendously value the ability to expose learners at all stages of medical education to patients and clinical problems in the real world. Community engagement with the corrections system, public hospitals, the Veterans Affairs medical center system, and universities where student mental health services are provided all give opportunities to medical students, residents, and fellows to prepare for careers serving patients in the environments where they receive care in the community.

Joseph B. Layde, M.D., J.D.

The connection between methamphetamine use disorders and HIV/AIDS has been well documented in the literature. Scientists at major academic centers have utilized fMRI, brain tissue analysis from autopsies, neuropsychological testing, and a variety of other scientific approaches to understand addiction and the effects of methamphetamine in those with and without HIV/AIDS. Communities, however, see methamphetamine causing friends and loved ones to participate in unsafe sex, commit crime, become homeless, and in some cases, develop recurring psychosis and debilitating depression.

I see the marriage of academia and community as a critical link between the abstract and the concrete. This union provides a venue where fMRI results are understood in the context of community observations, such as why a college student would decide not to use a condom when under the influence of methamphetamine. The observations of the local bathhouse employee are given as much cachet as a research scientist. The community learns from academia and vice versa.

Lawrence McGlynn, M.D.

Community-academic partnerships provide community leaders with an approach to help shape research that addresses their community's needs. Community-academic partnerships can facilitate the implementation of research by drawing upon the community partners' extensive knowledge of their community and building upon their already well-established relationships within it.

Cheryl Koopman, Ph.D.

I am dedicated to forging community-academic partnerships. Without these relationships I could not create the synergy needed to best serve the community populations I work with. I have worked on both sides of the relationship, and now my charge is to wear both hats simultaneously. The synergy I can achieve is unbelievable. But the balance is sometimes a challenge. And acting as liaison twixt the two

can be fun and often humorous. Sometimes each partner has such a different mind-set, it's as though they are from different planets but have the same ultimate goal. I sometimes feel like a translator or, better yet, an ambassador.

Daryn Reicherter, M.D.

### **Questions: How Does Someone Learn to Engage with Communities in a Manner That Is Respectful and Leads to Strong Partnerships? How Did You Learn?**

By being curious and learning about their mission and their process. By being humble and recognizing that one may not have anything to contribute to an existing system, but one may most definitely have something to learn.

Victor G. Carrion, M.D.

My approach to engaging communities in my academic endeavors is to identify a key leader in the community who is trusted and respected and to work with that person to build a bilateral relationship. By that I mean that, while the research outcomes might not always directly and immediately impact the community, there would be some type of indirect benefit to the community, such as skills building, mentorship, or other opportunities.

Yvonne Aida Maldonado, M.D.

The best way to learn how to work with a community in a respectful manner is to work with someone who is doing it well. This is how I learned.

Cheryl Gore-Felton, Ph.D.

First, find the “elder” of the community and engage in dialogue. Second, listen to their needs and not yours. Third, you never can become culturally competent but one can learn cultural humility.

Michele Barry, M.D.

Understand what the community's needs are from their vantage point. Ask the community members for their ideas on how to approach the issues. Don't be afraid to ask the members what certain terms mean, but speaking their vernacular may be seen as patronizing. Do not be apologetic for our academic standing—in the academic-community partnership, members usually take pride in the accomplishments of other members.

As in many areas of life, I learned my lessons by trial and error. I also attended a number of national conferences, leading to working relationships with subject-matter experts, and I continue to benefit from their expertise. Much of my learning,

however, came from my own mistakes. At one point I lost a significant number of group members. I could not understand why, for I had made their lives easier by doing much of the grunt work myself. As a result of my actions, they felt left out and obsolete. Luckily, the community is a forgiving lot, and they did not stay away for too long.

Lawrence McGlynn, M.D.

Academic psychiatry and community psychiatry have to be approached with the same level of respect. Whether these groups are formally collaborating or not, they are partners in mental health. We are all colleagues. We should sit at a round table without hierarchy. I learned this by doing it for my whole academic and community career.

Daryn Reicherter, M.D.

I draw upon resources from the literature (such as [1]) that suggest several elements to the participatory partnership:

- Recognizes community as a unit of identity
- Builds upon strengths and resources within the community
- Facilitates collaborative partnership in all phases of the research
- Integrates knowledge and action for mutual benefit of all partners
- Promotes a co-learning and empowering process that attends to social inequalities
- Involves a cyclic and iterative process
- Addresses health from both positive and ecological perspectives
- Disseminates findings gained to all partners

David Wyatt Seal, Ph.D.

A major source of learning how to engage with a community partner is to pay attention to what the community partner says and does. Key actions for showing respect are active listening and expressing appreciation for actions taken on behalf of the project. Keeping promises builds trust and strengthens partnerships.

The funding agency for much of my community-based research ...does an outstanding job of educating both academic and community partners in how to build strong partnerships. This education has been provided through conference and workshop presentations, newsletters and other educational materials, and conference calls in which the program officer checks in with community and academic partners. I have also learned a great deal about how to engage with my community partners from reading what others have published on related topics such as on community-based participatory research.

Cheryl Koopman, Ph.D.

Willingness to be taught and acknowledgement of one's own ignorance are prerequisites for learning. Universities do not always nurture these traits in faculty, so one must unlearn the socialization we are subject to as "academic experts" and admit that there are many things we don't know and there are many people who know them but don't have fancy letters after their name. Professors are supposed to profess, but I have personally learned more in my community work when I talked less and listened more.

Keith Humphreys, Ph.D.

### **Question: What Are Some of the Things That You Have Observed That Get in the Way of Partnership-Building?**

Although integration of systems is good in concept, the idea may be threatening to the identity of existing organizations, especially if these identities have been built to hold a certain amount of power and personal capital. Cooperation, co-location, and collaboration are more tolerable terms and may organically lead to integration.

Victor G. Carrion, M.D.

Mistrust. Often I have gone into communities where I was not the first researcher to come, and there were hard feelings left over from previous experiences. In these instances, I had to learn patience and to build my relationships with key community members over time. Finances and resources can also get in the way of building effective partnerships. It is important to treat community partners as key personnel on the project with salary support, resources, and positions that demonstrate a true partnership. The manner in which the data are analyzed and interpreted can break the strongest of relationships if not discussed early in the partnership development and throughout the project. Community interests may not line up with research or scientific interests, and balancing these perspectives is important.

Cheryl Gore-Felton, Ph.D.

Arrogance. Ideology. Rigidity. Political tone deafness. Grandiosity. Self-righteousness. Inability or unwillingness to say, "I don't know" or "I'm truly sorry." They are all unhelpful, on either side of the academic/community divide.

Jack Drescher, M.D.

Poor communication around goal sets and expectations can cause rifts. My experience is that the academic's goals should always be in keeping with the mission of the partner. For instance, if an academic wants to develop a training opportunity for residents and the community partner wants clinical time, this could be a "win-win" for both groups. But poor communication could misconstrue the process. Also being clear in communication about data collection is important. This also should be a

“win-win” for both groups, yet, if poorly communicated, this can lead to the impression that the relationship is one-sided (the academic center grabbing data and leaving).

Daryn Reicherter, M.D.

There are, at times, different agendas held by community partners and educational institutions. Understandably, community organizations hope to obtain excellent medical services through affiliation with a medical school, whereas they may not be as tuned into the realities of medical education in the medical school setting. Working through those issues of sometimes competing agendas is important and, if not done correctly, can get in the way of partnership building.

Joseph B. Layde, M.D., J.D.

In the end, I think turf, ownership, control, and ego are the main partners. Most “community-academic partnerships” involve doing *to* or doing *for*, not doing *with*. Transcendent partnership involves community working *with* academia toward common shared goals. Issues to address and resolve include ownership and control; research versus service delivery; time orientation; ensuring program/research integrity; overcoming status quo; gaining broad-based support; overreliance on being experts; funding versus community priorities; and competition for existing community resources.

David Wyatt Seal, Ph.D.

### **Question: What Are the Three Things You Wish You Had Known When You First Started Doing Work With Communities?**

I wish I would have known to be patient. Like any important relationship, it takes time to build a trusting and collaborative relationship with community partners. One meeting may not be enough. In fact, you might have to attend some community events, even those that at the time do not seem relevant to your interests.

Find the gatekeeper. Every community has a person who is the social glue. It is the person who knows the key people in the community who are the decision makers or who influence the decision makers. Once you find the gatekeeper, recruit them to be part of the team. Their presence on the project helps to build trust with community members, enabling the community to feel comfortable with the research team.

Create partnerships across all aspects of the project. This includes the planning phase and, in some instances, the grant writing phase. Ideally, community members should have key roles on the project and share in the resources and finances of the project. An example of this is when I test a novel intervention in the community, I will

hire a community member to be an interventionist. Usually, this person is part of a venue (e.g., clinic, community center, community-based organization) where the study is taking place. This enables the knowledge to remain in the community and assists in the uptake and dissemination of effective interventions. It also reduces the perception that researchers just want to “take” from the community to “build their own careers” and give nothing back. Indeed, there is often a sense that research can partner with a community in ways that enhance quality of life and improve health outcomes.

Cheryl Gore-Felton, M.D.

First, I wish I had known that in many community settings (e.g., schools, public housing projects, social service agencies) people have already had the experience of being studied before and not getting anything out of it. One thus often has to overcome the understandable belief among some community members that research will not be of value to them.

Second, I wish I had known how useless many theories developed in the rarified atmosphere of academia are in communities and therefore that dropping these conceptual frameworks was sometimes necessary to truly understand what was going on.

Third, I underestimated the amount of knowledge already present in communities and took a while to realize that I had as much or more to learn from them as I did to teach.

Keith Humphreys, Ph.D.

How to speak every language in the world.

How the money structure in public health works and the nature of the competition for limited mental health dollars, private and public.

That patience and a yielding attitude are more valuable than any other asset. Lao Tzu asks, “Do you have the patience to wait till your mud settles and the water is clear? Can you remain unmoving till the right action arises by itself?” He must have had these partnerships in mind!

Daryn Reicherter, M.D.

### **Question: How Has Working with Communities Changed the Nature or Effect of Your Work?**

Bringing health care access and equitable care to different cultural communities has been the core of my career.

Michele Barry, M.D.



I have been able to examine complex psychological and social problems in ways that would not have been possible without my community partners. I would not have been able to develop an adolescent HIV prevention intervention for teens living in low-income housing developments or work with men and women living with HIV/AIDS and experiencing trauma symptoms. The community organizations and the people who devote their time to the mission of service have enabled me to create interventions that directly impact the lives of the people who participate. I have adopted and have been adopted by several communities where I have worked. This type of personal connection makes the work very meaningful. It is no longer just about the results of study, but it is about the lives of the participants and the communities in which they live. Many partnerships translate into long-lasting friendships that extend beyond the last participant and the last paper written.

Cheryl Gore-Felton, Ph.D.

Early in one's career, it usually feels inherently good to succeed by academic criteria (e.g., your latest paper comes out). But as time goes by, most people ask themselves "Who cares?" For me, the answer to that is in the community and not in the university. Even though I am proud, for example, of the research I have done on community-based self-help groups for chronic diseases, my greatest sense of "meaning" comes from my direct contact with the people in those groups, seeing them better manage their illness, forge happier lives, and take care of each other.

Keith Humphreys, Ph.D.

For those in academic environments, a successful community partnership brings personal satisfaction unlike those found in any other academic endeavor. Community partnerships keep those of us in academia grounded in the core values and intentions that often led us to our careers.

Steven Adelsheim, M.D.

It is the cornerstone for effectiveness in both my academic capacity and in my ability to create change in public mental health.

Daryn Reicherter, M.D.

Dealing with the fiscal realities of community organizations has made me sensitive to how psychiatric care can take place outside of the academic ivory tower. For instance, learning about different limitations on the pharmacological formularies of prisons, county hospitals, and VA medical centers has made me more sensitive to real-world limitations on the possibilities of affordable care. I think it is also important for medical trainees to be exposed to those realities.

Joseph B. Layde, M.D., J.D.

My work has always been about community partnership. However, I think I have gained significant appreciation for what it takes to develop and build transcendent partnership being in academia.

David Wyatt Seal, Ph.D.

## Reference

1. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health*. 1998;19:173–202.