Commentary: Community Partnered Research: Driving Sensemaking, Managing Knowledge, and Moving Mental Health Care to New Heights

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COMMENTARY: COMMUNITY PARTNERED RESEARCH: DRIVING SENSEMAKING, MANAGING KNOWLEDGE, AND MOVING MENTAL HEALTH CARE TO NEW HEIGHTS

Junius J. Gonzales, MD; Carmen Moten, PhD, MPH

Longstanding gaps between research and practice, research and policy, and policy and practice impede the sustainability of high-quality health services delivery and often inadvertently contribute to disparities in healthcare access, processes, and outcomes. Why do these gaps exist? Explanations embrace multiple reasons and acknowledge the interactions between factors such as financing and organization of healthcare; attitudes, beliefs, and knowledge of patients, families, providers and policymakers; and the research or evidence base for decision-making. To complicate matters, these factors are in constant change. For high disease-burden conditions, such as mental disorders, which also have an early age of onset, a traditionally and predominantly linear biomedical/healthcare research process—from basic science to clinical treatment innovations to effectiveness and services research—is insufficient to meet both today’s suffering and tomorrow’s sustainability of innovative changes. Fortunately, new initiatives from the National Institutes of Health (NIH) offer opportunities for multilevel change in the medical research enterprise. From NIH’s Roadmap Initiatives, two parts are relevant to work with communities, research teams of the future and re-engineering the clinical research enterprise (nihroadmap.nih.gov). The articles in this special issue represent bold examples for those two initiatives by extending the role and work of communities and not just limiting that work to patient communities or community-based providers. The work here, in no uncertain terms, cogently and potently demonstrates who else can and should be part of a research team. Fortunately, the recent trans-NIH program announcement on community-based participatory research is a preliminary but correct step in these directions.

The National Institute of Mental Health (NIMH) has a long history of concern and action related to community participatory work and health disparities in racial/ethnic populations as well as other underrepresented groups (ie, women, children, disabled) in order to fulfill its mission. In particular, the services research initiatives over the past few years have lead the way in a commitment to true community partnerships, realizing that the work must go where the people live and work day to day. Housed in the Division of Services and Interventions Research are such items as:

- Research programs in health disparities, sociocultural work, and dissemination and implementation;
- Program announcements to build research infrastructure, through sustainable partnerships, in communities to take advantage of real-world and real-time changes and study them;
- Recent special initiatives to ready state mental-health systems to implement evidence-based practices and efforts to study readiness; and
- Workshops bringing together intervention and services researchers with academic management experts who study strategic and organizational change.

Communities, regardless of definition used, are changing and dynamic collectives. The work showcased in this special issue is timely, innovative, and absolutely necessary. Yet significant obstacles abound, the intense labor and psychic energy necessary to establish true partnerships between different cultural realms, the competing demands of people’s day-to-day lives, the devaluation of this work in traditional academic departments, and ever-decreasing funding streams.

These challenges come with opportunities at many levels. In our minds, perhaps the two most interesting scientific challenges/opportunities have to do with: 1) identifying the key ingredients or mechanisms for successful partnerships and change; and then 2) determining what modes of knowledge management and transfer are best used for which situations and when. These two areas are, of course, connected. The reports in this special issue demonstrate a high level of rigor in mixed-methods work and innovation by tapping unique settings such as a film festival or using an audience-response approach for data collection. However, some might argue that these approaches are routine for disciplines such as marketing and consumer behavior work. Regardless, this kind of transfer from other disciplines will be critical in moving community-partnered research forward. But what key elements make things work and why? What mechanistic roles, if any, do leadership and/or teamwork really play? Can knowledge sharing or transfer occur between interested parties and stakeholder groups to truly move science into the public?

On the issue of mechanisms, the process data captured in many of these reports is or will be critical to understand from as
An understandable and relevant model is presented by Nancy M. Dixon in her book Common Knowledge. Dixon wrote that first an organization must create common knowledge before it can leverage it. She explains that organizations must make a conscious effort to discuss experiences, review them, and to capture the knowledge gained from the experience. The next part of the model is being able to transfer this knowledge either to other people or maybe even the same team that originally created the knowledge in order to capitalize on the information by preventing future mistakes and/or learning a valued process. Next, Dixon explicates five categories of knowledge transfer: serial transfer, near transfer, far transfer, strategic transfer, and expert transfer. This taxonomy is useful in describing who is involved, what types of knowledge are transferred, why, and for what ends.

Other models and frameworks attempt to explain the same thing, the creation and transfer of knowledge. Although the models vary somewhat in presentation, each essentially emphasizes that knowledge cannot simply be codified. Knowledge has to be internalized by the individual or team in order to be applied to a particular task. The papers in this issue demonstrate that this internalization is occurring. However, don’t we all wish for one repository of living information about all community-partnered health research efforts in this country? Herein lie opportunities for the authors of these papers, as well as for funders. Pechura outlines some possible steps for foundation funding approaches and calls on additional partnerships. Perhaps one concrete target can be in the realm of managing knowledge. Tremendous economies of scale, scope, and learning can emerge with blended funding, and anecdotal evidence points to duplication of efforts in research and innovative service demonstrations. While federal research funding has some different aims and requirements, previous “mixed-motive” partnerships between that funding and foundations have been successful. Furthermore, given the nature of this community-partnered research, a third potential partner—business sectors in those communities—must be engaged early.

Finally, community-partnered research can be an exciting and enriching approach to understanding and dealing with ethics in clinical research. Emanuel et al’s framework articulates six of seven requirements of ethical clinical research that are flexible enough to accommodate the needs of community-partnered research and that view community as a unit that is more than simply the sum of its individual members. Thus, they remain: 1) social or scientific value; 2) scientific validity; 3) fair subject selection; 4) favorable risk-benefit ratio; 5) independent review; and 6) informed consent. In addition, Chen et al suggest that the seventh requirement, respect for potential and enrolled participants, be amended to “respect for potential and enrolled participants, community, and research partners” to acknowledge that separate attention should be paid to relationships on these three levels.
In conclusion, community-partnered approaches to mental-health research promise to deepen our scientific bases of knowledge in the areas of health promotion, disease prevention, and health disparities. Community-partnered research processes can generate better-informed hypotheses, develop more effective interventions, and enhance the translation of the research results into practice. Specifically, involving community and academic partners as research collaborators may improve the quality and impact of research by:

- Increasing the potential for translation of evidence-based research into sustainable community change that can be disseminated more broadly and affect public health and policy;
- Enhancing the NIH mission and philosophy so that it values the involvement of the community in research and creates language that expresses this value (eg, establish grant criteria that require community involvement in the research and where appropriate, require researchers to demonstrate active involvement with the community in issues it considers important);
- Developing intervention strategies that incorporate community norms and values into scientifically valid approaches;
- Increasing accurate and culturally sensitive interpretation of findings;
- Encouraging change in the culture of the scientific community to ensure that mental health research is viewed in the context of a long-term commitment to the community, not a one-time research study (eg, provide funding to sustain community-based groups over time so that they become invaluable sources for participants; focus on building these groups as ongoing relationships rather than transactional partners);
- Enhancing recruitment and retention efforts by increasing community engagement and trust;
- Encouraging research institutions to look for new partnerships and other ways to bridge the gap between clinical trial treatment and options for additional treatment in the local healthcare system beyond the clinical trial;
- Increasing relevance of intervention approaches and thus likelihood for success;
- Targeting interventions to the identified needs of community members, stockholders, advocacy groups, family members, patients;
- Setting the expectation across the entire research community, NIMH-funded research and beyond, that study results and outcomes should be shared with the research participants and the larger community promptly and consistently;
- Documenting and publishing “best practices” from efforts to reengineer the clinical research enterprise as soon as the NIMH begins to see results, so that progress in improving community trust in mental health research grows rapidly and steadily.

REFERENCES