Aligning the Goals of Community Engaged Research: Why and How Academic Medical Centers Can Successfully Engage with Communities to Improve Health

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Abstract:

A key goal of the National Institute of Health’s Clinical and Translational Science Awards (CTSA) consortium is improving the health of the nation through community engaged research (CEnR). CEnR requires a mindset and skills that leadership in Academic Medical Centers (AMCs) have not yet the opportunity to learn. This paper seeks to assist AMCs – both within the CTSA consortium and outside of it – in how to better engage with their communities and build a CEnR agenda. CEnR is defined as a cyclical approach to research that shares power and decision-making throughout the research process between scientists and community stakeholders and links research to a translational health agenda that changes behavior, structures and policies.

Five steps are suggested for AMCs to consider in working toward the development of a CEnR agenda, including:

1) Recognize that CEnR is “Real” Science
2) Define Community and Identify Partners
3) Learn the Etiquette of Community Engagement
4) Build a Pipeline of CEnR Researchers and
5) Improve Dissemination Plans.

AMCs are also encouraged to examine their own institutional structures and examine questions such as: Are institutions flexible, “community ready” partners? Do researchers use the term research “subjects” or research “participants”? Are there tenure and promotion paths for junior faculty interested in CEnR? Are members of institutional review boards trained in CEnR?
**Introduction:**

“Improve the health of the nation.”

The National Institutes of Health’s Clinical and Translational Science Award (CTSA) consortium has a number of goals, objectives and intentions, but none as lofty, broad and historically significant as “Improve the health of the nation.” Key to this objective is community engagement (CE) and community engaged research (CEnR). This paper seeks to assist Academic Medical Centers (AMCs) – both within the CTSA consortium and outside of it – in how to better engage with their communities and build a CEnR agenda.

CE and CEnR are defined differently by different stakeholders. For some CE and CEnR are simply processes that enable clinical research studies to successfully recruit broader and more diverse groups of participants in studies (often referred to as “subjects.”) For others they are processes that broaden the paradigm of research away from a sole focus on linear approaches of scientist-defined hypothesis, randomized-controlled trials (RCTs) and publication in academic journals and toward a cyclical process that shares power and decision-making throughout the research process between scientists and community stakeholders and links the research process to a translational health agenda that changes behavior, structures and policies.

It is this latter definition that this paper will focus on, but the first perception of CE and CEnR is important to address. While few people would not admit *not* wanting to improve the health of the nation, for many people, it is the processes of their profession that brings them satisfaction.
For bench researchers who enjoy the quiet and solitude of lab work, or deans of medical centers who enjoy the challenge of keeping up with cutting-edge clinical care, or hospital CEOs who enjoy the power and responsibility of providing clinical care, community engagement may seem to be only a means to their specific desired end: more study participants, more patients who choose a hospital, more grants and funding, etc. However, CEnR offers much more than greater participation for research and services, it improves and evolves science so that it does not just ask and answer questions but aligns itself with positive change in population health. Community engagement and CEnR requires a skill set and orientation that few clinical researchers and providers, deans of medical schools and CEOs of hospitals have yet been afforded the opportunity to learn. It requires that stakeholders in clinical research imagine larger goals for the questions they ask and think beyond the silos of their own discipline. It asks AMCs to learn to share power, decision, making and funds with stakeholders in their communities and it asks that researchers see their work as an investment in the future rather than a set of time-limited activities. The end goal is not AMC research for the sake of research or community involvement for the sake of community involvement, but rather, both of those concepts are in service to the larger goal of improving population health.

There is an increasing national focus on CEnR. For many decades communities have been defining problems, testing solutions and improving their own health outside of the purview of research institutions -- creating a wealth of models and ideas waiting to be tested broadly and scaled up.\textsuperscript{1-3} Congress authorized funding almost 10 years ago for the CTSA consortium out of a concern that money spent on research was not translating into improved health. The Obama administration in 2010 has elevated the priorities of improving health outcomes not just through
insurance reform but also through increased funding and support for community-engaged research.\textsuperscript{4,5} Furthermore, increased focus on prevention and primary care models that emphasize community engagement are receiving national and international attention.\textsuperscript{6,7,8} However, the stakeholders most crucial to this shift are those holding power in AMCs.\textsuperscript{9,10} A key challenge is to find ways to align the goals of medical school deans, hospital CEOs and leading clinical scientists with those of community stakeholders such as public health departments, grassroots organizations and non-profits, community clinics, neighborhood organizations, churches, city governments and many others so that while each entity may be enjoying the process of what they do, they are all working in concert toward one goal: Improving the health of the nation.

**Background of CTSA Consortium, CE & CEnR**

The CTSA consortium – launched in 2006 and comprised of 46 academic medical centers (AMCs) in 26 states – has as its primary goal to speed the process of translating basic research discovery into clinical application, clinical practice, and, ultimately, improved population health.\textsuperscript{11} The consortium is administered by the National Center for Research Resources (NCRR), part of NIH, and is organized into 13 key functional committees. The community engagement key function committee (CE-KFC) is comprised over 200 members from each CTSA institution and various federal agencies. Its mission is to implement a successful broad plan of community and practice engagement among the CTSA sites by sharing knowledge, expertise and resources. The goal of the CE-KFC is to effectively engage communities and practices in the translational research process via bidirectional dialogues. The main areas of focus include:

- community and practice outreach,
access and dissemination of the translational research process via bidirectional dialogues.

The specific milestones of the committee include: 1) developing a community engagement needs assessment; 2) generating a project registrar with the input of the NIH and other federal agencies, and community practices agencies and members 3) establishing partnerships for funding collaborative development of curricula and evaluation outcomes as well as metrics for community engaged research.

In conjunction with the Association for Prevention Teaching and Research (APTR), in 2008 the consortium hosted a series of regional workshops focused on community engagement. The discussions of these workshops were summarized into a monograph: “Researchers and Their Communities: The Challenge of Meaningful Community Engagement” available at: http://www.ctsaweb.org/index.cfm?fuseaction=committee.viewCommittee&com_ID=3&abbr=C

In 2010 the CE-KFC will publish a revised version of the CDC’s 1996 book “Principles of Community Engagement. Funded through 2011, the Community Engagement Consultative Service (CECS) is a service to all CTSA members affording the opportunity to bring in consultants to AMCs to assist in strengthening an institution’s capacity for community engagement.13

CE and CEnR research has roots not only in medicine but also in education, sociology, anthropology, ecology, public health, political science and other disciplines.14 The CE-KFC does not seek to invent and re-define CE and CEnR, but rather to customize and disseminate an already robust volume of literature and examples from other disciplines. The hope of the CE-KFC is to harness the power of interdisciplinary models of CE and CEnR into models of transformation applicable to AMCs.
The National Institutes of Health Director’s Council of Public Representatives (COPR) in 2010 developed a framework that includes a set of values linked with strategies and expected outcomes. COPR defines community engagement in research as “a process of inclusive participation that supports mutual respect of values, strategies and actions for authentic partnership of people affiliated with or self-identified by geographic proximity, special interest, or similar situations to address issues affecting the well-being of the community of focus.”

COPR identified 5 core principles: 1) definition and scope of community engagement in research 2) strong community-academic partnerships 3) equitable power and responsibility 4) capacity building 5) effective dissemination of plans.

Building on these principles, are five steps that AMCs can undertake to prepare their institutions for CE and CEnR. This is not a linear set of instructions but rather a set of considerations to undertake concurrently.

1. **Recognize that CEnR is “Real” Science**

While participatory approaches including Community Based Participatory Research (CBPR) have traditionally been the paradigm of public health, there is urgency for such approaches to be applied to all aspects to health and medical research agendas as it seen as the key to translation. As public health and medicine are pressed harder to adhere to “evidence-based medicine” – that is, practice that is guided by rigorously researched evidence that a treatment or intervention is effective -- and policy makers struggle to make decisions, there is a call for more evidence that is practice-based, that is, it demonstrates positive effects in “real
world” settings that are not as easily controlled.\textsuperscript{24,25} To address this complexity and research real world settings, CEnR approaches are essential. Multiple methodologies from other disciplines can and should be adapted and adopted to meet this challenge.

However, for biomedical academicians accustomed to difficult intellectual challenges, CEnR may seem “soft” or not intellectually rigorous enough to be “real science.” A comprehensive review of published CPBR studies by Viswanthan et al and published by the Agency for Healthcare Research and Quality (AHRQ) found that “[a]lthough the potential for trade-offs between addressing community concerns about research and maintaining high-quality study designs has been cited as a possible challenge to high-quality research, our review does not suggest a strong trend in the direction of solid community-based participatory methods combined with weak research design or measurement. Similarly, the strongest research methods do not appear to be combined with weaker community participation elements.”\textsuperscript{26}

One of the major obstacles to CEnR is a perception that randomized-controlled trials (RCTs) are the “gold standard” of biomedical research and that research approaches and methodologies from other disciplines are inferior. It is interesting to note that the roots of the biomedical RCT are in agricultural research. Famed English statistician (and controversial eugenicist) Ronald Fisher wrote of his experiments on corn in “The Design of Experiments” and in a letter to the British Medical Journal in 1936 advised:

“If, in this matter of experimental design, some other class of worker, such as veterinarians, bacteriologists, or vitamin chemists, had recently taken the lead in developing an improved
technique, eminently suitable to the needs of their colleagues in other fields, would it not be desirable to call the attention of others to their success? For reasons which seem principally to belong to the past, workers in the more academic subjects are not in the habit of expecting advances in theoretical knowledge, relevant to their own studies, to be introduced from agricultural research; this prejudice, I submit, makes it more than usually important to do it in this matter the justice which is its due.”

Today, there is still a hesitancy to borrow and adapt the scientific techniques from other disciplines. While RCTs are appropriate for many biomedical questions, the RCT focus on controlling for complexity sometimes makes it an inferior technique for complex questions. The main population health issues facing the U.S. today – chronic disease, infectious disease, and injury -- are issues in which personal knowledge, skills and behavior, community environmental factors, and policy choices all affect outcomes. Research that addresses these causes of death but fails to incorporate the complexity of their social determinants, will fail to translate into improvement in the human condition.

What techniques and methods will allow for the complexity of our most pressing questions and still be statistically and scientifically meaningful? Hawe et al propose adapting RCTs to allow for complexity. The authors write: “Many people think that standardization and randomized controlled trials go hand in hand. Having an intervention look the same as possible in different places is thought to be paramount. But this may be why some community interventions have had weak effects.” In this paper, the authors propose “a radical departure from the way large scale interventions are typically conceptualized [that could] liberate interventions to be responsive to
local context and potentially more effective while still allowing meaningful evaluation in controlled designs. The key lies in looking past the simple elements of a system to embrace complex system functions and processes.” For example, the question of what is standardized in a study might be considered. For example, is it best to standardize the components of study or the processes of a study? 28

In addition to problems of complexity, RCTs also pose ethical problems with many historically abused and clinically underserved communities who are hesitant to trust researchers. West et al propose alternatives to the RCT that empower participants instead of “control” for them. For example, in “randomized encouragement designs” participants are randomly invited to participate in one of the treatment conditions, but are allowed to decide whether to receive treatment. “Quantitative assignment designs” assign participants to treatment groups on the basis of a quantitative measure such as need, merit or risk. 29

Educational research and evaluation has long been employing alternative techniques for randomized trials by extending randomization to groups rather than individuals. 30, 31 With proper attention and control of “threats to validity” these designs can be very effective in community level studies. Chatterji argues for extended-mixed method (ETMM) designs than randomized field trials. ETMM designs “follow life-spans of individual programs/policy initiatives within particular environments, employing appropriate descriptive research methods in the early stages of program adoption and implementation followed by timely and judicious implementation of experimental designs at a subsequent stage.” 32
Addressing the 3rd Annual NIH Conference on the Science of Dissemination and Implementation: Methods and Measurement, Bruce Rapkin, PhD, Professor in Albert Einstein College of Medicine’s Division of Community Collaboration, advocated that scientific rigor does not equal the randomized trial and that communities of shared interest must form around learning systems that conduct successive studies leading to refinement of key distinctions among interventions, types of populations and settings. He also advocated for comprehensive dynamic trials that support learning systems by inventing and evolving interventions in place, drawing upon multiple sources of information gained during the conduct of an intervention. 33

2. Define Community and Identify Partners

How do we define “community?” There are multiple types and layers of potential community partners for AMCs to work with, including neighborhood organizations, community health practitioners and clinicians, governmental agencies, non-profits, advocacy organizations, schools, religious organizations, jails, neighborhood leaders, etc. AMCs interested in long-term CEnR research agendas need to identify the communities they seek to work with and identify partnerships. A first step in doing so might be to rethink and broaden who AMCs might consider “customers” and to carefully evaluate the goals technical, managerial, political, and cultural/social objectives of projects with community partners. 34 35

Community is a fluid concept, in which membership can be by choice or by innate trait such as gender, race, and sexual orientation. People hold multiple memberships in communities and researchers should view communities as systems composed of both individuals and sectors. 21 36
For example, AMC researchers wanting to partner with churches should be aware that members intersect with many other areas of the community such as schools, workplaces, senior centers and governmental agencies.

AMCs might form strategic partnerships with patients and families in specific disease areas to improve outcomes, as in the case with the Cincinnati Children’s Hospital did with families with children with Cystic Fibrosis to improve the continuous quality improvement (CQI) process in delivering care. Numerous partnerships exist between AMCs and community-based organizations. Some good examples can be found in the partnerships between AMCs in Massachusetts and the Center for Community Health Education Research and Service, Inc. (CCHERS) in Boston, Mass. or Charles R. Drew Medical University and Healthy African American Families in Los Angeles, Calif. Community-Campus Partnerships for Health published a compendium of case studies of Academic-community partnerships, “Achieving the Promise of Authentic Community-Higher Education Partnerships: Community Case Stories” that features stories of successes and failures of these types of partnerships.

Every AMC should be closely aligned with city, council, and state public health departments and safety net clinics. AMCs, public health departments and safety net clinics all imagine themselves as being “the front line” of health care. They’re all right and all need to work together. Public health departments already have access to epidemiological data, partnerships, and the capacity to affect large environmental changes. The Institute of Medicine (IOM) issued a landmark report in 1998 challenging the public health community to “think more strategically, plan more collectively, and perform more effectively.” The report inspired a number of
initiatives and changes that emphasize partnerships including the Mobilizing for Action through Planning and Partnerships (MAPP) process developed by the National Association of County and City Health Officials (NACCHO)\textsuperscript{40}. MAPP is a community-driven strategic planning process for improving community health that can be a useful starting point for AMCs.\textsuperscript{41} A good example of an academic-health department collaboration is the Durham Community Health Network.\textsuperscript{42}

Safety net clinics are in the best position to address health disparities. Too often, fiscal and bureaucratic barriers discourage AMCs from working with departments while public health departments and clinics are weary from evaluation and research that siphons off limited funds for services. Successful partnerships include the University of New Mexico’s Health Extension Rural Offices (HEROs)\textsuperscript{43,44}, Duke University Medical Centers division of community health and its “Just for Us” program\textsuperscript{45,46}, and Denver Health’s relationships with safety net providers.\textsuperscript{47}

Other crucial partners for AMCs are community-based physicians. The majority of care delivered in this country is delivered in private physician’s offices, community, homeless, migrant, and school-based health centers, free clinics, and other settings outside of academic centers. Partnering with these professionals – doctors, nurses, physician’s assistants, dentists, social workers – in crafting a research agenda and in disseminating results is crucial to translational medicine.\textsuperscript{48,49} Practice-Based Research Networks (PBRNs) are uniquely equipped to both help define a practice-based research agenda, participate in research and translate findings quickly into practice.\textsuperscript{50,51} Research that has the most impact 1) asks the questions physicians want answered 2) allows flexibility and physician involvement 3) leaves behind paths
for physicians to change practice (technology, information, etc). For example, primary care physicians, who see ever rising rates of chronic illness, want help in finding ways to prevent illness. Research agendas need to reflect helping physicians to work with their patients to prevent illness. Good examples of PBRN partnerships include the Michigan Clinical Research Collaboratory and the Oklahoma Physicians Resource/Research Network.

Networks of health centers, many funded by HRSA, exist in most states and are increasingly interested in participating in research. These groups are coalitions of health centers which work together to implement health information technology and many are funded by HRSA. Although these networks are controlled by health centers, they often involve other providers, such as hospitals, health departments, and specialty care providers, in order to assure the continuity of care for health center patients. Their data collecting ability and community connections make them ideal partners to consider.

3. **Learn the Etiquette of Community Engagement**

Before AMCs can build a CEnR agenda, they must first learn the principles of CE. There is often a long list of perceived benefits of community engagement to researchers but for many underserved and historically abused communities, medical research is viewed as either a tool used to denigrate their community or as a threat to services for funding. Researchers need to be honest and clear about the purpose and goal of research; to do homework about the community’s demographics and economics; and to be helpful and humble. AMCs need to clearly understand that communities have the right to self-determination and to decline researchers’ views, and
work toward building authentic, long-term partnerships that focus foremost on community identified needs rather than researcher identified needs.

In 1997, the Centers for Disease Control and Prevention prepared the booklet “Principles of Community Engagement.” The CTSA CE-KFC is currently revising the booklet, but many principles remain the same: Learning about a community’s history, culture and environment, share power and show respect, include partners in all aspects of planning, and pay community partners fairly.

- Learn first about a community in terms of its history, culture, economic conditions, political and power structures, norms and values, demographic trends, history, and experience with engagement efforts. Over the course of several Association of Prevention Teaching and Research (APTR) sponsored regional community engagement workshops held in 2008 and 2010, successful researchers talked about the time and humility it takes to get to know a community. Too often researchers approach a community with a fully formed research proposal without understanding a community’s needs and history. Worse, well-intentioned researchers themselves may not understand their own institution’s history with a community. Many researchers and community partners reported that the best way to build this knowledge base of a community is through “unfunded connections” when there is not a specific project or grant in mind. Eliminating the restrictions inherent in having to answer to funding organizations can allow for more creativity and flexibility. For example, many researchers reported joining or forming local health coalitions and groups even though they weren’t funded to do so.
Forging relationships in these groups without a specific project or agenda in mind both builds trust and enables true partnership when applying for funding.  

- **Share Power and Show Respect.**
  
  During APTR regional meetings on community engagement, researchers and community partners discussed the importance of “power and respect.” Researchers need to be aware of different meanings and how communities conceptualize the varieties of power (level of education, length of residency, record of activism, etc). Open and respectful discussion of power issues can enable people to examine the power dynamics which exist in a community and in a partnership. Sometimes identifying issues and discussing their history can make partners more comfortable talking about sensitive issues. Sharing power involves respecting what all groups bring to the endeavor, and building partnerships that are equitable and based on what each organization is able to contribute. Partners can acknowledge each others’ contributions by encouraging all to participate in discussions and in making decisions. One key aspect of power sharing is learning the appropriate ways of showing respect. Academics often rely on listing degrees earned and positions held to communicate power and importance. Partnerships may consider listing members’ non-academic degrees and honors, such as positions held in religious organizations or local groups. Omitting everyone’s credentials may or may not be appropriate depending on the group. Similarly, the use of first names only instead of “Dr.” and “Ms.” may or may not be appropriate depending on the group. Respect also means thinking of small, polite things that might not occur to researchers but are important to community partners such as holding meetings in settings where it is easy for partners to park or are close to mass transit (as opposed to the complicated pay parking decks of AMCs); providing food
and beverages at meetings; offering child care; and remembering to celebrate successes together.  

- **Include partners in all phases of research, including planning.**  
  A key aspect of CBPR that should apply to all forms of CEnR is planning research with community partners. Before writing research grants it’s important to include community partners in defining the research agenda and in planning new projects. Planning processes could include mission statements with partners, memorandums of understanding (MOUs) clarifying terminology, expectations and timelines, and focus groups with the underserved. Similarly including community partners in decisions to change plans, especially when decisions involve delays in original timelines is also critical. One interesting example of community planning at every phase is the Toronto Teen Survey, a partnership between academic researchers, community partners and a diverse cohort of teenagers living in Toronto.  

- **Pay Community Partners Fairly.**  
  Community partners—whether they are a physician group, a non-profit neighborhood improvement organization or a public health clinic—are often skeptical of partnerships with academic institutions that expect engagement without compensation. Again, researchers and community partners at regional workshops had many points of advice, including: 1) Partnership involves sharing resources and AMCs should not expect participation without compensation. 2) Sorting out the accounting hassles of sharing grant money can be challenging, so when writing grants and working with foundations, work with the community in planning and establish ways to share money. 3) Establish upfront guidelines for sub-contracts such as how to track spending and activities, how to
document receipts, etc. If accounting departments at AMCs are not familiar with how to do this, institutions should provide and encourage “how-to” training that provides reporting rules for full-time equivalents and financial requirements. It is also often necessary to provide community partners with similar training and technical assistance for their accounting staff as well. Workshop attendees emphasized that fundable roles for community partners are not “one size fits all” solutions and each situation will vary. What works for a physician group will not work for a non-profit activist group. AMCs need to be flexible with policies and procedures.

Jones and Wells conceptualize the research activities of their partnership between Charles Drew Medical University and Healthy African American Families as having three implementation stages: “vision, valley and victory.” The “vision” is developing a shared view of the goal, the “valley” is doing the collaborative work and facing challenges, and the “victory” is completing the product and celebrating the process. Minkler in examining the commonalities of a set of ten case studies of CBPR studies resulting in policy changes identified several success factors related to etiquette, including: “A high level of mutual respect and trust among partners,” “Commitment to “doing your homework – finding out what other communities had done, who held decision-making authority,” and “facility for building strong collaborations and alliances with numerous and diverse stakeholders beyond the formal partnership.”

4. **Build a pipeline of CEnR researchers.**
In addition to supporting researchers currently interested in CEnR, AMCs must also take an active role in building a pipeline of future researchers. Long-term, committed partnerships between communities and research institutions requires building a training pipeline that sparks interest in research in pre-college students, makes community engagement a required competency for doctoral and medical student, and rewards researchers for community-engaged projects that lead to improved outcomes. This can be done at a number of levels. For example, AMCs can provide training for all university students and researchers through required coursework, self-paced modules and certification. At Duke University Medical School, any medical student, resident or researcher wanting to work in the community must go through a certification process. MD-MPH programs, such as the one offered by the University of North Carolina-Chapel Hill, is a good example.

AMCs should also take an interest in building the pipeline of potential researchers outside of their own institution. There are many opportunities to link to current activities or build new initiatives with local health departments, museums, libraries, schools, arts organizations and schools to host events, lecture series, health fairs, symposiums etc. and educate the community about health research, as well as learn about community capabilities and other forms of research and practice. This could be effective both in educating the community at-large about research in a fun and recreational way, as well as encouraging young people (particularly those from communities underrepresented in medical research) to consider careers in health care research. In the previously cited example of the Toronto Teen Survey, in which teens were hired as advisors and worked with researchers to design and implement teen sexual health surveys, the
project also strengthened the research capabilities of teens and community partner organizations.\textsuperscript{60}

Another example is to offer a community-based research tools and traineeships to develop the research capacity of medical and social service professionals who service underserved neighborhoods but have limited research experience. The Health Resources and Service Administration (HRSA) funds 53 Area Health Education Center (AHEC) programs and 221 affiliated AHEC Centers in 45 states and the District of Columbia.\textsuperscript{61} These centers offer key links to educating health providers who might not typically be engaged in the research process. The CTSA’s PRIMER project is a toolbox of resources and information for building research capacity among practice-based physicians.\textsuperscript{62}

5. **Improve Dissemination Plans**

To truly include community partners in building a CEnR research agenda, dissemination plans and strategies need to evolve beyond traditional medical journals. AMCs reward researchers for how often they publish in medical journals intended to communicate with other scientists, most of these journal articles rarely trickle down to the level of non-scientists. Instead researchers must work with their partners to creatively push their information in a variety of ways. Nelson et al provide information and case studies in disseminating findings in “Making Data Talk: Communicating Public Health Data to the Public, Policy Makers and the Press.”\textsuperscript{63} Cases of good dissemination cited by the book include:
• CDC obesity researchers switching from a table format showing the rise of obesity to color coded maps of the U.S.\textsuperscript{64}

• Dissemination to policy makers advocating for folic acid fortification of the food supply\textsuperscript{65}

• Communicating death rates from smoking to teenagers through the use of visuals instead of numbers.\textsuperscript{66, 67}

During the APTR sponsored regional workshops on community engagement, researchers and community partners offered many ideas on dissemination, including:

• It is important to plan for dissemination at the beginning stages of a study and think through privacy and ethical concerns of reporting back results, best modes of communication for the intended audience, and how to time when information is released.

• IRB considerations sometimes prohibit researchers from contacting research participants directly without their consent. Considering “opt-in” provisions in IRBs (“Is it OK to contact you with results?”) might encourage more participants to receive information. It is important to work with IRBs at the beginning stages of a project to address this.

• Another challenge of CEnR is giving community members information in a timely and useful way so that they get knowledge out of the experience. Too often, waiting until the end of a study to report outcomes will be too late to keep participants engaged. It is important to find ways to keep partners updated throughout the process.

• Community physicians are also too often overlooked at the end of studies. If they aren’t highly motivated to do research, they might be unlikely to refer patients for further studies if they are never informed of study outcomes. AMCs should not forget referring
physicians in dissemination strategies as they are vitally important to 1) translating findings into improved care 2) referring future patients for future studies.

- Most importantly, it is important for AMCs to be creative in disseminating findings and information to the community. From listservs and emails, to “open mic” nights and town hall meetings, AMCs need to stop thinking of dissemination as a linear process, but rather a cyclical process that feeds the community information in formats that effect change and implementation and elicit new research questions. For many researchers this is uncharted territory. While marketing, journalism, public relations and other disciplines can help, AMCs should start evaluating their own best dissemination practices and sharing with each other.\textsuperscript{12}

**Challenges and Recommendations:**

Currently, the U.S health care system ranks low compared to other industrialized nations and yet costs taxpayers and consumers considerably more than residents of other countries. The biggest difference between the U.S. and other countries is universal access to care.\textsuperscript{68} Health reform legislation enacted in 2010 should put the nation on a path toward increased access, but the health disparities that lead to uneven quality and high costs will persist without a CEnR agenda that finds answers to both medical and public health questions.

One of the biggest barriers AMCs face in working toward a translational, CEnR agenda is themselves. The historical structures and processes of an AMC – including the complexities of how IRBs operate, accounting practices and indirect funding policies, and tenure and promotion
paths – can inhibit and stifle partnerships outside of the AMC. Changing institutional culture starts with the leadership and commitment of top decision-makers in an institution. Before engaging in the five steps discussed in this paper, it is important to examine the internal culture of one’s own AMC and decide whether and what kinds of changes are needed. This examination should include the following types of questions: 1) Is an institution a flexible and “community ready” partner? 2) Do researchers use the term research “subjects” or research “participants”? 3) Are there tenure and promotion paths for junior faculty interested in CEnR? 4) Are members of institutional review boards trained in CEnR?

For example, tenure policies will likely need changing. Tenure policies and rewards need to account for the different skills and requirements or CEnR. Faculty involved in CEnR must balance and sometimes prioritize the needs of communities over the needs their own research needs, but to do so can often be detrimental to their careers. AMCs can and should change tenure and promotion policies to encourage rather than discourage community engagement. Steiner et al write a case study of how the Department of Family Medicine at the University of North Carolina at Chapel Hill School of Medicine attempted to encourage and reward community engagement among physicians. The authors identified four key lessons: “(1) If academic departments wish community service to be a central part of their mission, they need ways to institutionalize community engagement within organizational structures. (2) Community engagement can be scholarly. (3) If faculty members are to be recognized for their service activities, measures are necessary to determine what constitutes “excellence” and “scholarship” in community service. (4) Scholarship of community engagement goes beyond performing service activities in the community.”
Another major issue facing many academic researchers doing CEnR across the country is the Institutional Review Board (IRB) process. At many institutions, IRB members are not familiar with CEnR and the ethical considerations for communities might come into conflict with ethical considerations for individuals. AMCs can work to train IRB administrators and clinical researchers who are used to traditional research terminology in the language of community engagement and how to harmonize protection for individuals and communities. IRBs might also consider having CEnR experts available for consultation when they are considering CEnR protocols.

Countless other barriers to CEnR—small and large—exist throughout the culture and structure of an AMC. Numerous researchers and community partners have remarked in regional workshops that “our nation’s bookshelves are much healthier than our people as study after study is published but never translated into every day practice.” But these barriers and problems are not insurmountable. For the U.S. health care system to be someday ranked as the best in the world, leadership at every level of the health care system—from policy makers to community members—need to envision improved quality and access to care, prevention of disease, and safer, healthier, happier communities (as well as new treatments that save lives). AMC leadership, specifically, needs to shift from a mindset of thinking of “the community” as a means to an end—carrying out clinical trials—to the end goal itself. By aligning the motivations and goals of their researchers, clinicians, and community members into a vision of a healthier population, AMC leadership will not just improve their own institutions, but improve the health of the nation.


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