

## MODULE 3: BUILDING SUCCESSFUL HEALTH CENTER-ACADEMIC RESEARCH PARTNERSHIPS

### Why Health Centers are Ideal Partners for Research

Health centers are already regarded as ideal partners and settings for research for many reasons, including:

- **Patient and Case Mix:** Health centers provide valuable opportunities to fill critical gaps in knowledge regarding medically underserved populations. Their patients are predominately uninsured, publicly insured, minority, low income, and experience compounding social determinants that impact their access and outcomes – the same populations often excluded from research. Health centers' patient populations experience high rates of chronic disease and some of the most acute health disparities but are traditionally under-researched.<sup>1</sup> Little is known about how health centers' complex populations respond to certain illnesses and interventions and which interventions work best in resource-poor settings and how demographic factors, such as geographic location, race and ethnicity, insurance status, affect medical and behavioral conditions.<sup>2</sup> However, populations served by health centers also exist in other settings, though in many cases not in the same high concentrations. Health center research has potential application to these people wherever they are served.
- **Community Experience:** Health centers have an intimate bond with their community; a majority of their governing boards is made up of local community members while health centers' involvement in their communities through community activities and needs assessments has led to a deep understanding of the people they serve and emerging issues in their community. Health centers have the knowledge and trust to work with these under-researched communities who often express deep distrust of research and have the ability to engage and activate their patients. This trust

can help speed the translation of research into practices and communities.

- **Broad Array of Services:** Health centers provide services not traditionally seen in other primary care settings, such as dental, behavioral health, pharmacy, and enabling services and have experience integrating services. Moreover, their enabling and social support services break down access barriers in an effort to improve receipt of care and patients' understanding of their care.
- **Quality Improvement (QI) Experience:** Health centers can build off of their existing QI infrastructure to engage in research. Currently, 90% of health centers already use Electronic Health Records (EHR).<sup>3</sup> Health centers recognize the importance of data collecting and reporting as a means to identify health priorities in their community and strategies to improve outcomes. (See Section II, A: Building Off QI Capacity) As a result, health centers already have a wealth of data on uninsured populations and special populations, such as homeless populations and migrant/seasonal farmworkers. Many health center clinicians and leadership also have experience evaluating their care, most evident by participating in the national HRSA-funded Health Disparities Collaborative initiative, which aimed to improve care for people with chronic conditions through partnerships, care transformation, and evaluation.
- **Previous Research Experience and Interest:** More than half of health centers already engage in research while many health center clinicians either already have experience participating in research or are interested in engaging in research to help improve health outcomes and clinical care.
- **Role in Health Reform:** Health centers are already major players in outreach and enrollment efforts under Medicaid expansion and health insurance exchanges. They are also playing an important role in system

transformation to facilitate achievement of the national Triple Aim of lower costs, improved population health, and better care experiences, by becoming Patient-Centered Medical Homes (PCMHs) and by participating in new models of care integration.

- **Dissemination Infrastructure:** Health centers' memberships in state Primary Care Associations (PCAs), Health Center Controlled Networks (HCCNs), PBRNs, and specific member organizations like AAPCHO, Healthcare for the Homeless, Migrant/Farmworkers, and the National Association of Community Health Centers (NACHC) create an infrastructure to speed the dissemination of information and evidence-based approaches.

Overall, what makes health centers ideal research partners is their deep understanding of the context in which care is delivered and the circumstances in which patients live, work, and seek care. This knowledge is critical for designing effective studies, interpreting results, and implementing research findings into new settings. Working with health centers can often lead to long-term partnerships that open doors to work on future research projects and gain Service Learning experience. Such collaborations with the largest primary care network in the country can make a significant impact on health and health care by generating and advancing knowledge on medically underserved communities that experience the most acute health disparities.



### Keys to Successful Research Partnerships with Health Centers

It is important to understand that while health centers have infrastructure that provides a launchpad to engaging in research, most do not have the resources to divert staff time away from patient care. For example, an IT staff at a health center may not be able to do their current job and support 20% FTE for research. Since health centers' main focus is on health care delivery to meet their patients' needs, partnerships with other organizations and institutions can open doors for health centers to engage in research and further build their existing infrastructure and capacity. A recent national survey found that nearly all (94%) health centers who participate in research do so through partnerships with external researchers.<sup>4</sup>

Most health center partnerships are with either academic institutions (71%) or with other health centers (38%). Only 7-12% of health centers reported partnering with large-scale federally



supported academic institutions, such as the National Institutes of Health (NIH) Clinical and Translational Science Award (CTSA) program, the Centers for Disease Control (CDC) Prevention Research Center (PRC) program, or with primary care based research networks, such as PBRNs. However, health centers may unknowingly partner with academics who belong to these institutions.

Although most health centers consider their partnerships as successful, the most commonly reported challenges to partnerships include constraints of staff time and budget due to an inequitable distribution of resources between partners as well as factors relating to the perception that the health center was more of a site for research rather than a true research partner. Many health centers reported that external partners did not understand the health centers' priorities and its community and encountered a lack of engagement with both the external research and the health centers' internal staff.<sup>5</sup>

Partnerships that are formed in a Community-Engaged Research (CEnR) context are particularly valuable to health centers. CEnR is a framework or approach for conducting research that involves the community in a meaningful way to both conduct and translate research in the context of people's lives to improve health. Community-engaged research exists as a continuum, with varying levels of community participation based on the community's desire, willingness, and ability.<sup>6</sup> However, in community-engaged research, there is always the opportunity for the community to participate because their partnership with academics is based on mutual trust and respect. Health centers operate in special circumstantial conditions compared to more traditional and less resource-poor settings, so knowledge of their environment and community is critically important for research. CEnR prioritizes the community's unique context and provides opportunities for the external researchers to interact with the community and learn about its distinct characteristics while the community uses its unique knowledge and resources to help shape and implement the research project. CEnR's collaborative and bidirectional approach is congruent with health centers' operation and is a valuable way to engage communities that are typically left out of traditional research.

On the Community-Engaged Research spectrum is Community-Based Participatory Research (CBPR). In CBPR, all partners, including community partners, are actively involved from the beginning of the research process and are considered equal and full partners based on the unique contributions each partner makes.<sup>7</sup> For example, community partners in CBPR partnerships do not merely provide input on research objectives but identify which issues are of highest importance to the community; they are involved in designing the study and data collection rather than merely providing input to ensure that the design is culturally appropriate; they work with academics to interpret the results rather than merely

providing comments on the results, and so on. While there are many benefits to CBPR, it requires long-term relationships to achieve it.

Using varying levels of the community-engaged approach, common strategies contributing to successful research partnerships with health centers have included a shared vision among all research partners, transparency, clarity of roles and responsibilities, collaborations in recruitment and retention of patients, demonstrating feasibility and cost-effectiveness, sharing systems and processes, engaged leadership, familiarity with the health center and its community, and building infrastructure and capacity for research at health centers.<sup>8</sup> It is important that academic and external researchers show their interest in investing in the health center and community by ensuring that research capacity building and accompanying resources are built into and are explicit goals of the research partnership. Health centers and community members involved in the research project should be equitably compensated for their time and expertise through funding and recognition. Touring the health center, holding meetings in the community rather than the university, and disseminating research results back to the community in a way that is meaningful and useful to the community are other ways to build trusting and lasting relationships.<sup>9</sup>

While Community-Engaged Research is a useful way to show interest and commitment to the community and ensure the health center is an equitable partner, it is important to keep in mind that some health centers will prefer to be more directly and actively involved or simply have the resources and staff to be more directly involved while others may prefer to be more "hands-off" due to differences between health centers' capacities and priorities.

It is important to establish principles when partnering with health centers to show

commitment and understanding, with building research capacity as an explicit goal. Several

institutions have created helpful principles for community-academic partnerships.

### What Does Engagement Mean?

There are many types of engagement depending on the context and who is involved. For example, patient engagement and community engagement are related forms of engagement but are not the same. However, both are significant in the health center context. Patient engagement is critical for identifying research topics of interest to patients to improve health outcomes as well as empowering patients to be more active in their health care. Community engagement is crucial to help break down barriers to participating in

research as members of the community become more knowledgeable and trusting of the research process and project. Community engagement can narrow health care disparities and improve population health. Both patient and community engagement can lead to more long-term and sustainable interventions, changes, and improvements because patients and members of the community are involved and invested in the process and outcomes. These concepts are fluid and may have different meanings depending on who defines them as Table 2 below demonstrates.

**Table 2. Examples of Different Definitions of Community Engagement by Different Organizations**

Definition	Organization and Citation
<i>“The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.”</i>	Centers for Disease Control and Prevention. Principles of community engagement (1 <sup>st</sup> ed.). Atlanta (GA): CDC/ATSDR Committee on Community Engagement; 1997.
<i>Process “where the practice community and community physicians are engaged in research and collaborate with academic researchers.”</i>	National Institute of Health Clinical and Translational Science Award. Westfall JM, Mold J, Fagnan L. Practice-based research—“Blue Highways” on the NIH roadmap. JAMA 2007; 297(4): 403-406.
<i>A process that “helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options...It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices.”</i>	Patient-Centered Outcomes Research Institute Board of Governors March 2012 Meeting Notes. Accessed January 10, 2014 from <a href="http://www.pcori.org/research-we-support/pcor/">http://www.pcori.org/research-we-support/pcor/</a> .

Community-Engaged Research is a critical component for many different types of research but especially for translational research, Comparative Effectiveness Research, health

services research, and policy research. It not only helps the translation of research in terms of speeding implementation and dissemination through community-appropriate means, but it

also focuses on community's needs and priorities and identifies under what conditions and under what populations do certain clinical models and interventions work most effectively. In Community-Engaged Research, community partners are meaningfully involved, with opportunities to participate at any part and in any capacity depending on the community's desire and ability.

Different definitions of community can change the objectives of research so it is important to discuss what definition of community should be used in particular contexts and which perspectives should be taken into account. There are multiple ways to view community based on different perspectives. For example, there can be communities around geospatial parameters (neighborhood, town), collective identity (racial/ethnic, religious, sexual orientation, disability), social interaction (garden club, cycling club), and collective action (labor unions, community coalitions).<sup>10</sup> The Community Health Applied Research Network (CHARN) recognizes and respects that people are members of multiple communities. They honor this diversity by referring to "the community of \_\_\_" rather than "the community". Different levels of community can include communities of patients, communities of clinicians, communities of organizational staff, and so on.<sup>11</sup>

While engagement and community can mean many different things, it is important to approach the health center or community from the beginning of the research process so they can provide input. **From there, the health center can decide on the extent and involvement of its engagement.** As mentioned in the section above on successful partnerships, some health centers may prefer to be more directly and actively involved while others may prefer to not be as involved. Similarly, some health center staff may be willing to spend their own personal time to engage in research while other health center staff may prefer to participate in research that more seamlessly integrates into their own daily clinical operations and provides minimal disruption to their daily responsibilities. Alternatively, some health centers may not be able to be as involved because there are not sufficient resources allocated to them by academics due to academic budget constraints, such as high indirect rates that take away funds from the awarded grant money and leave fewer resources for community partners if they are not already written into the grant. Health centers need adequate financial, resource, and staff support written into the grant to be engaged in research and should be a serious consideration of any research partnership.



### Reaching Out to and Negotiating With Health Centers

Different operating environments, community-based priorities, resource constraints, and patient- and community-centered concerns mean health centers will require plenty of lead time when establishing partnerships. It is important to approach the health center at the beginning or before the research proposal



planning phase to build a trusting and transparent relationship and to discuss how to address gaps in the health center's research infrastructure and capacity. The decision to engage in research is not taken lightly so it is important to factor in time to allow health centers to discuss the proposal with key decision makers, address concerns, modify it, and to receive approval from the appropriate decision-makers. Health centers want to have

the chance to ensure that the research aligns with their priorities and that it fits into their day to day operations. It is also important to build in time in advance to negotiate details, from research methods to roles to budgets, while discussing the gaps in research infrastructure and capacity.

There are multiple points of engagement at a health center though each health center is different, so who to engage may differ between health centers. Regardless of who is initially approached, multiple staff will need to become involved in the decision-making process and the research implementation process. These will most likely include clinicians, Chief Medical Officers, Quality Program Officers, Chief Executive Officers, research staff (if any), board members and a growing number of patient research advisory groups. These are all key decision makers who help set a research agenda, define research priorities, and ultimately decide what research to support and pursue.<sup>12</sup> Some health centers and Health

Center Controlled Networks (HCCNs) even have research workgroups or boards that make these decisions or “research collaboration questionnaires” for academics to fill out before deciding to participate in research so that they become aware of what will be needed both in resources and in processes for the health center to participate in research. This decision-making process can lengthen the research planning time, but it is a crucial step in creating a successful and acceptable proposal. NACHC and Primary Care Associations (state-based health center associations) can often help facilitate introductions and partnerships with health centers should they feel the research would be of interest to health centers and if the partner is earnest and willing to engage the health center as active partners. Other providers and academics with academic medical institutions that have health professional training activities at health centers can provide starting points for research by building off existing collaborations.



### Key Resources for More Information

- Minkler, M. and Wallerstein, N. (eds.) (2008). *Community-Based Participatory Research for Health: From Process to Outcomes*, Second Edition. Jossey-Bass: San Francisco, CA.
- Israel, B.A., Eng, E., Schulz, A.J., and Parker, E.A. (eds.) (2013). *Methods for Community-Based Participatory Research for Health*, Second Edition. Jossey-Bass: San Francisco, CA
- MacQueen KM, McLellan E, Metzger DS, Kegeles S, Strauss RP, Scotti R, Blanchard L, Trotter RT. What Is Community? An Evidence-Based Definition for Participatory Public Health. *American Journal of Public Health*. 2001; 91(12): 1929-1938.

- Oneha MF, Proser M, Weir RC. Community health centers: why engage in research and how to get started. Brief by the National Association of Community Health Centers and the Association of Asian Pacific Community Health Organizations. 2012. <http://www.nachc.com/client//WhyDoResearch.pdf>
- Jester, et al. National Survey of Health Centers’ Research Participation: Activities and Needs. (forthcoming publication in CES4Health).
- Michener L et al. Aligning the goals of community-engaged research: why and how academic health centers can successfully

engage with communities to improve health. *Acad Med.* 2012 Mar;87(3):285-291.

- AAPCHO Community Criteria for Research Fact Sheet

- DC Collaborative principles

- University of Minnesota--Partners in Research: Curricula to Prepare Community and Faculty for CBPR Partnerships, 2010. <http://ces4health.info/find-products/view-product.aspx?code=T63W5WBC>.

- University of Utah Guidelines for Community-Based Research Partnerships, an orientation to university researchers and community members who wish to form partnerships for community based research. <http://bit.ly/k0WnzP>

- Yale Center for Clinical Investigation, CARE: Community Alliance for Research and Engagement, Principles and Guidelines for Community-University Research Partnerships, [http://care.yale.edu/resources/96362\\_PrinciplesforU-CPs\\_000\\_tcm368-55861.pdf](http://care.yale.edu/resources/96362_PrinciplesforU-CPs_000_tcm368-55861.pdf). Also lays out partnership strategies, partner expectations, and relevant definitions.

- WCCHC's Principles

- CHARN's Principles: <http://www.kpchr.org/charn/Public/index.aspx?pageid=3&SiteID=1>

- Ahmed SM and Palermo AG. Community engagement in research: frameworks for education and peer review. *Am J Public Health.* 2010 Aug;100(8):1380-7.

- Academic Readiness Questionnaire to Engage with Community Health Centers

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<sup>1</sup> Wendler, D, Kington R, Madans J, Van Wye G, Christ-Schmidt H, Pratt LA, Brawley OW, Gross CP, Emanuel E. Are racial and ethnic minorities less willing to participate in health research? *PLoS Med.* 2006; 3(2):e19. Kressing NI, Meterko M, Wilson NJ. Racial disparities in participation in biomedical research. *J Natl Med Assoc.* 2000;92:62–69. King TE. Racial disparities in clinical trials. *N Engl J Med.* 2002;346:1400–1402.

<sup>2</sup> Oneha MF, Proser M, Weir RC. Community health centers: why engage in research and how to get started. Brief by the National Association of Community Health Centers and the Association of Asian Pacific Community Health Organizations. 2012.

<sup>3</sup> US Department of Health and Human Services, Health Resources and Services Administration, Bureau of Primary Health Care. Uniform Data System. 2012.

<sup>4</sup> Jester et al, 2013

<sup>5</sup> Jester et al, 2013

<sup>6</sup> MacQueen KM, McLellan E, Metzger DS, Kegeles S, Strauss RP, Scotti R, Blanchard L, Trotter RT. What Is Community? An Evidence-Based Definition for Participatory Public Health. *American Journal of Public Health.* 2001; 91(12): 1929-1938.

<sup>7</sup> W.K. Kellogg Foundation's Community Health Scholars Program. 2001. Israel, BA, Eng E, Schulz AJ, and Parker EA (eds.) (2013). *Methods for Community-Based Participatory Research for Health.* Second Edition. Jossey-Bass: San Francisco, CA. Minkler M and Wallerstein N. (eds.) (2008). *Community-Based Participatory Research for Health: From Process to Outcomes,* Second Edition. Jossey-Bass: San Francisco, CA.

<sup>8</sup> Devoe JE, Gold R, Spofford M, Chauvie S, Muench J, Turner A, Liumahuwa S, Nelson C. Developing a network of community health centers with a common electronic health record: description of the Safety Net West Practice-based Research Network (SNW-PBRN). *J Am Board Fam Med.* 2011; 24(5):597-604. Davis RM. A collaborative approach to the recruitment and retention of minority patients with diabetes in rural community health centers. *Contemp Clin Trials.* 2009 Jan; 30(1): 63 – 70. Khankari K, et al. Improving colorectal cancer screening among the medically underserved: a pilot study within a Federally Qualified Health Center. *J Gen Intern Med* 2007 Oct; 22(1): 1410 – 1414. Jester et al, 2013.

<sup>9</sup> Oneha, MF & Beckham S. Re-examining community based research protocols. *Pacific Public Health* 2004; 11(1): 102 – 106.

<sup>10</sup> Israel, BA, Eng E, Schulz AJ, and Parker EA (eds.) (2013). *Methods for Community-Based Participatory Research for Health.* Second Edition. Jossey-Bass: San Francisco, CA. Minkler M and Wallerstein N. (eds.) (2008).

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*Community-Based Participatory Research for Health: From Process to Outcomes*, Second Edition. Jossey-Bass: San Francisco, CA.

<sup>11</sup> Khankari K, et al. Improving colorectal cancer screening among the medically underserved: a pilot study within a Federally Qualified Health Center. *J Gen Intern Med* 2007 Oct; 22(1): 1410 – 1414.

<sup>12</sup> Davis RM. A collaborative approach to the recruitment and retention of minority patients with diabetes in rural community health centers. *Contemp Clin Trials*. 2009 ;30(1):63-70.