



NATIONAL ASSOCIATION OF  
Community Health Centers



# Building Research Partnerships with Community Health Centers: A Toolkit for Academics

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## INTRODUCTION

As community and patient-centered providers, the national network of Community, Migrant, Homeless, and Public Housing Health Centers brings a unique perspective to the circumstances in which their patients live, work, receive care, and change behaviors. Also known as Federally Qualified Health Centers (FQHCs), health centers have a long history of patient engagement in health care delivery and community wellness programs. These practices are rooted not only in their population health and wellness improvement missions but also in their federally mandated program requirements to be actively directed by a consumer-majority governing board and responsive to needs identified by the community.

Health centers' uniqueness in terms of structure, perspective, and stakeholders make them prime partners for community-engaged translational research. Most are eager to expand their research partnerships and capacity as a means to fulfill their missions of improving community health and narrowing health disparities. The fundamental principle in any

partnership is that both sides need to benefit. Understanding the context in which health centers operate and how that drives their research priorities will help researchers understand how to match their research objectives with those who provide health care to the populations in the communities they serve.

Increasingly health centers are engaging in or being asked to participate in research and evaluation. Health centers have long been recognized as both nimble in their ability to design, implement, and evaluate health care delivery innovations on patient care and robust enough in terms of its scalability to potentially 9000 sites nationwide. However, many health centers are not engaged in research, and most may not be engaged to the level they desire because of competing priorities, lack of staff time and funding, the need for research training, and collaborative partners who understand health centers' day-to-day demands and workflow.



### About This Toolkit

This toolkit is meant to provide researchers with the information they need to understand how the health center model can support their research initiatives. It is intended to depict how health centers operate, their research interests, their research experience, and their research needs. The modules in this toolkit will illustrate why health centers can be ideal research partners and why the unique richness of the populations in community based settings served by health centers can enhance research

objectives. The toolkit will discuss potential opportunities researchers may have by engaging health centers and their populations as well as tips for building sustainable partnerships. We believe that by including health centers and the populations they serve as research partners, researchers can expand the depth of their research initiatives from bench to bedside to a more novel approach to include bench to bedside "to the community" for more sustainable and lasting change.



### **How To Use This Toolkit**

This toolkit recognizes that expanding research concepts to include community populations involve different processes. The following modules in this toolkit are intended to provide a general overview of health centers and their patient populations, health center research experience, expectations and needs of health centers as research partners, and suggestions for establishing a research partnership with a community partner committed to your research initiative. The toolkit will demonstrate how health centers' unique structure and context necessitate certain models of engagement and research participation that are community-based; however, the toolkit will provide general

steps to take when engaging health centers. We encourage all those interested in working with health centers to read this document in its entirety; however it is a modulized resource for ease and convenience. It is important to note that reading this resource is no substitute for familiarizing yourself with a local health center and potential research partner. The information presented here represents national data; however, each health center is unique with different environments, resources, and priorities. Working with health centers to conduct research can lead to very rewarding partnerships with long-term benefits and significant impact.

## MODULE 1: AN INTRODUCTION TO THE COMMUNITY HEALTH CENTER MODEL

### Unique Model of Care that Facilitates Research

The Federal Health Center Program, also known as Community, Migrant, Homeless, and Public Housing Health Centers,<sup>1</sup> began as a “War on Poverty” program targeting medically underserved communities. From their founding under the Public Health Services Act of 1965, health centers were designed to remove entrenched barriers to care, improve population health, narrow health disparities, and generate system-wide health care savings. In fact, a wealth of literature demonstrates their successes along these lines, as well as their capacity constraints.<sup>1</sup>

Health center program requirements are grounded in federal statute and regulation, touching on governance, need, services, financing, and management – which in combination establish a unique, patient- and community-centered approach to care that sets health centers apart from other providers. These include:

- *Community governed.* At the heart of the health center model is the requirement that at least 51% of health center governing board membership be made up of active patient users, thereby ensuring that health center programs are responsive to community needs and priorities. This governance structure oversees all areas of health center operations – including the hiring and firing of health center Directors – thereby functioning as something much more than advisory boards.
- *Locate in or serve medically underserved areas.* These areas are designated by the Health Resources and Services Administration (HRSA) as having: too few

primary care providers, high infant mortality, high poverty, and/or high elderly populations.<sup>2</sup> These areas tend to have high risk for health disparities and poor health outcomes and have high need for health care services.

- *Serve all without regard to insurance status of ability to pay.* Health centers provide services to anyone and everyone who walks through their doors. They provide discounts to uninsured patients in need with fees adjusted based on an individual’s ability to pay.
- *Provide comprehensive, coordinated primary and preventive care services.* Health centers must provide a broad array of primary and preventive care, as well as “enabling services” designed to remove barriers to care. Health centers are also encouraged or in some cases required to provide behavioral health, dental, vision, and pharmacy services. Health centers are also required to collaborate with other local health and social services providers, though strong referral networks in many places do not exist.
- *Provide culturally competent care.* Services are required to respect and respond to their patient population’s cultural preferences.
- *Conduct ongoing needs and quality improvement (QI) assessments.* Health centers must have QI and quality assurance programs, and must conduct regular, formal assessments of community needs.
- *Report data.* Health centers must report data annually to the federal Health Resources and Services Administration (HRSA) on patients, services, quality, and finances.

These requirements are designed to ensure that health centers improve access to high quality, affordable care in communities at high risk for health disparities. They also lead to diverse patient populations, unique staffing, and community expertise – all of which make health centers prime vehicles for community-driven research.

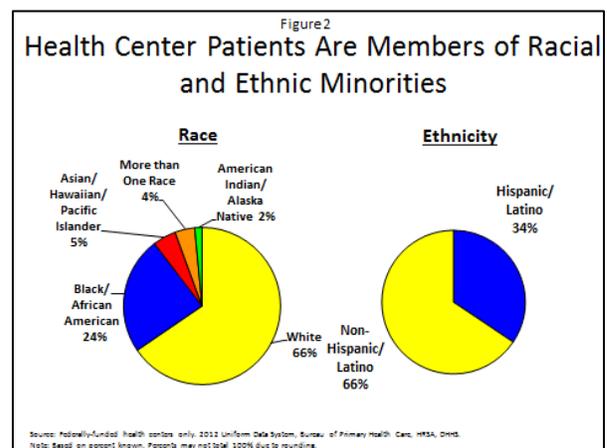
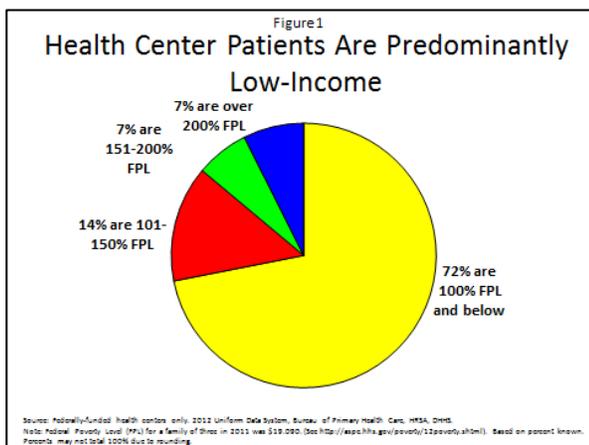
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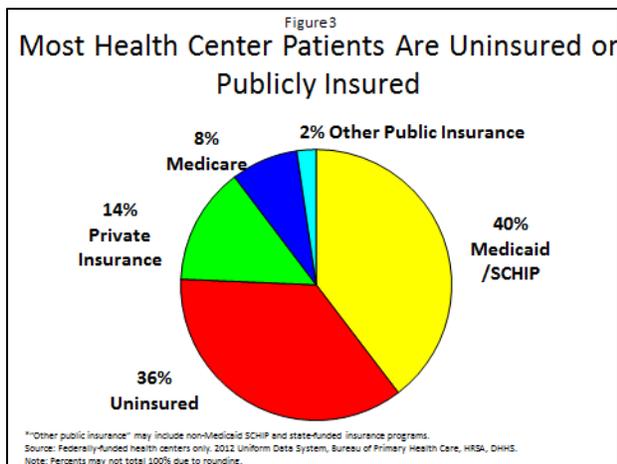
<sup>1</sup> Health centers are also commonly referred to as Federally-Qualified Health Centers (FQHCs), which refers to a Centers for Medicare and Medicaid Services payment designation.

## Health Center Patients Make Up Priority Populations

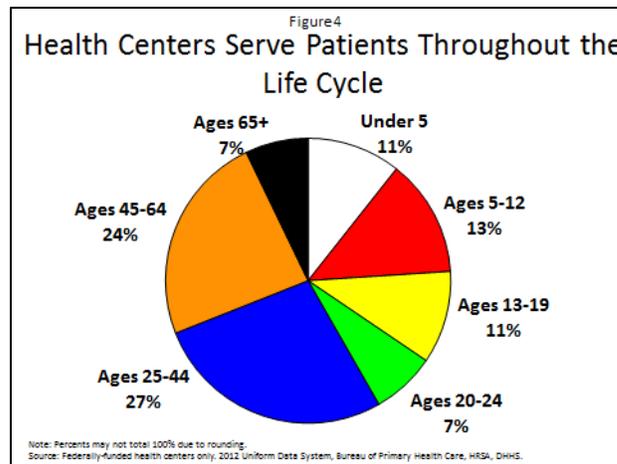
Health centers currently serve over 22 million medically underserved populations at high risk for acute health disparities. Nearly all health center patients are low income (below 200% of the Federal Poverty Level) with 72% having incomes at or below poverty (Figure 1). Patients also tend to be members of racial and ethnic minority groups (Figure 2). At the same time, 36% of health center patients are uninsured and another 40% depend on Medicaid (Figure 3). About half of health center patients reside in rural areas while the other half tend to live in economically depressed inner city communities. In addition, they serve over one million homeless patients, and another million migrant and seasonal farmworkers.

Because of the mandate to serve all patients regardless of insurance or ability to pay, health centers serve disproportionately more Medicaid and uninsured patients than mainstream providers. Furthermore, they have extensive data on these populations that most providers do not. They currently serve 1 out of every 7 Medicaid beneficiaries in the U.S. and 1 out of every 5 low-income uninsured.<sup>3</sup> The following figures provide an overview of the populations served by health centers nationally, but the characteristics of a population served by a particular health center may differ from others and be driven by the unique characteristics of the geographic setting they serve. Overall, working with health centers offer insights and potential understanding of populations under-represented in mainstream populations.





Health centers serve populations that often experience high levels of chronic conditions. Top health conditions diagnosed at health centers are hypertension, diabetes, overweight and obesity, depression, and asthma—many of which are considered priorities for research and action by Healthy People 2020 and the Agency for Healthcare Research and Quality (AHRQ) as Table 1 below shows.<sup>4</sup> They also serve patients

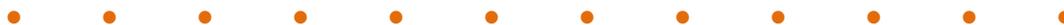


who experience co-morbidities and face compounding social determinants of health, such as homelessness, language barriers, poverty, and lack of social support. Few health center patients have access to innovative research occurring in other practice-based settings. Patient and community engagement is critical so that patients are informed and are aware of opportunities to participate in research.

Table 1. Health Center Data by AHRQ Priority Populations

AHRQ Priority Populations	Health Center Demographics
Low-Income	93% of patients are ≤200% FPL 72% of patients are ≤100% FPL
Female	59% of patients are female
Chronic Illness	More than 40% of encounters concern a chronic illness*
Rural	48% of health center grantees are in rural communities
Minority	62% of patients are racial/ethnic minorities
Children	32% of patients are under age 18
Elderly	7% of patients are age 65 and older

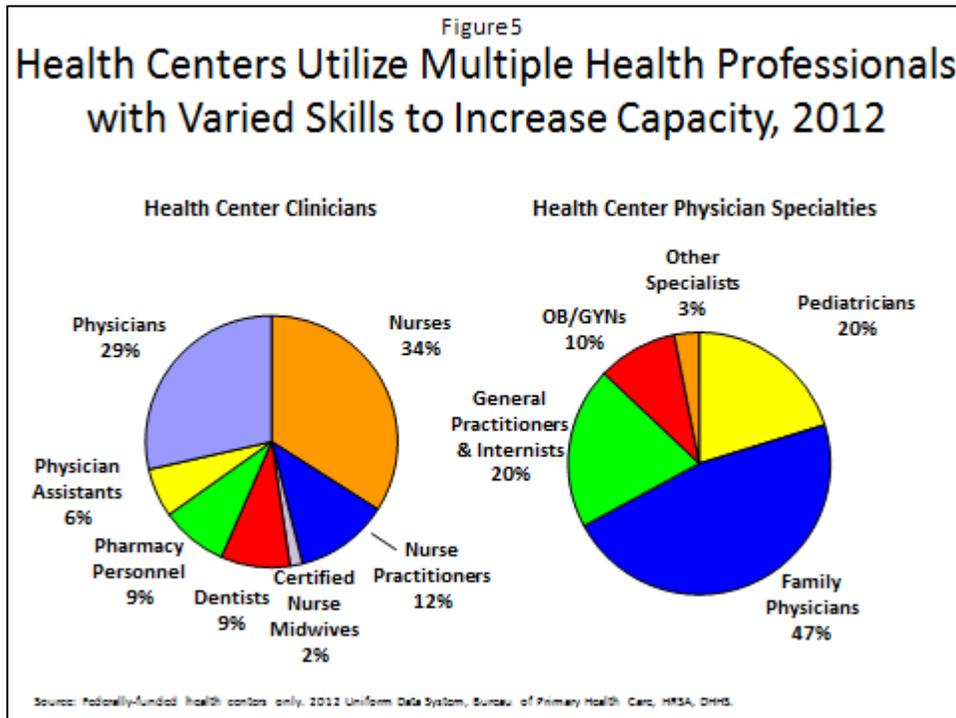
Source: 2012 Uniform Data System, Bureau of Primary Health Care, HRSA, DHHS.



### Health Centers' Broad Array of Services and Staffing

Health centers already have much of the “foundational” infrastructure for researchers to develop varying proposals for study. Health center staff consist of multi-disciplinary team of health care professionals, who are engaged in quality improvement activities and who use health information technology to track and evaluate performance measures. However, few health centers have staff whose duties solely include research<sup>5</sup>; therefore, infrastructure often does not include research administrative infrastructure.

Given their patients’ broad health care needs, health centers provide services not traditionally seen in other primary care settings, such as dental, behavioral health, pharmacy, and enabling services that facilitate access to care. These include case management, outreach, translation, transportation, health education, exercise programs, nutritional assistance, insurance enrollment, home visitations, housing assistance, job training, and support groups. Health centers achieve such comprehensive care through a diverse staff model that utilizes multiple health professionals with varied skills, such as physicians, nurse practitioners, physician assistants, community health workers, and case managers (Figure 5).



Health center staff work in teams to ensure the complex health care needs of their patients are met. Health centers consistently work to improve their performance. As of March 2014, 73% of health centers are participating in a

Patient-Centered Medical Home (PCMH) Initiative and 44% had achieved PCMH recognition.<sup>6</sup> This presents both opportunities and challenges for engaging health centers in research. Health centers are eager to evaluate

their progress in serving as PCMHs and improving performance, particularly on the value they generate to payers, patients, and communities, but often lack dedicated research staff and expertise to effectively engage in evaluation studies. Transforming care often requires changing how care is delivered and

coordinated, as well as infrastructure enhancements, and therefore generates many research or evaluation questions. It also means that health centers are eager to translate proven innovations – another area in which research can assist.



### Health Centers' Revenue Streams

Health centers run on tight operating margins and all rely on grants to ensure services provided are comprehensive and to ensure they meet their mandate to serve all without regard to ability to pay. In fact, health centers currently serve 1 in 5 low-income, uninsured individuals. Current funding sources make it difficult for most health centers to engage in research studies. For example, many health centers do not have indirect rates. Therefore, researchers should be prepared to provide some level of financial and staff support to health centers directly for their involvement.

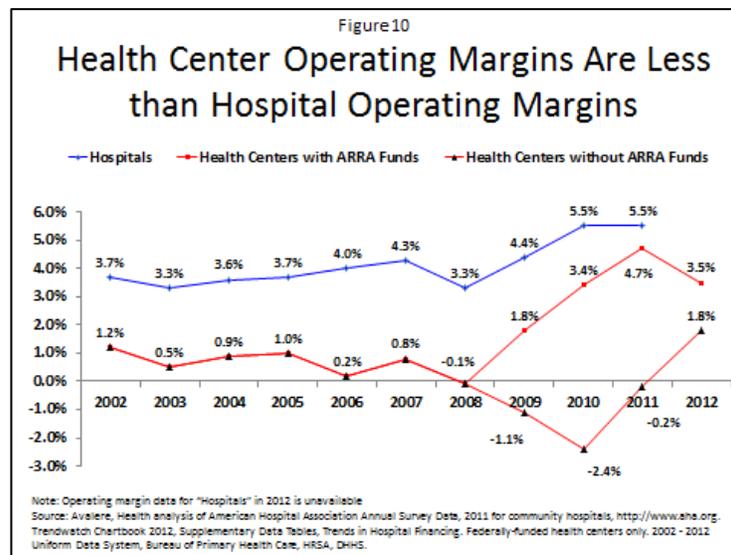
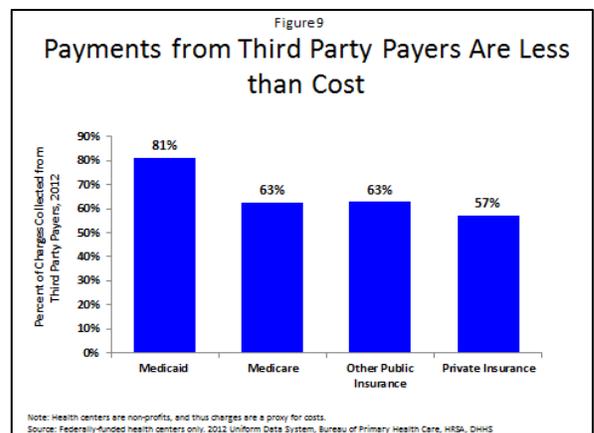
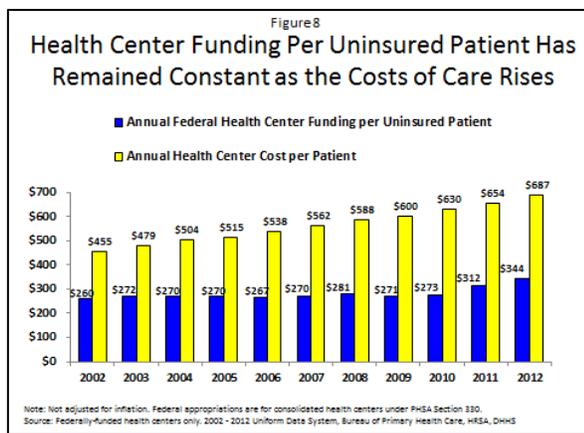
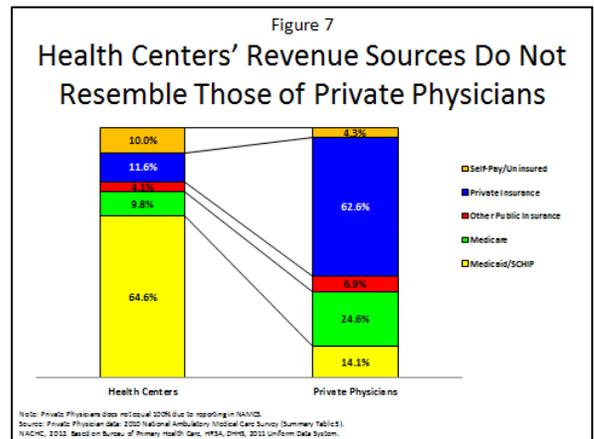
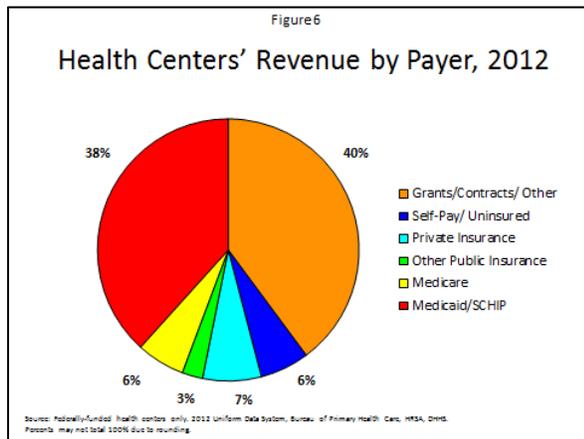
Health centers have diverse funding streams that include grants and third party payers (Figure 6). Reflecting their predominately publicly insured and uninsured patient mix, health centers' largest source of revenue nationally is Medicaid and their second largest source is federal health center grants<sup>7</sup> (Section 330 under the Public Health Service Act). These federal grants are part of their core program infrastructure and are not intended for research



purposes. As Figure 7 below depicts, health centers' revenue mix differs greatly from those of office-based primary care physicians.

Despite the mix of revenue sources, health centers' operating margins are less than other providers', with some health centers running on negative operating margins. This is because health centers' financing is structured around their mission of improving access to care and decreasing health disparities. Federal grants have not kept up with the costs of health care (Figure 8), and health centers actually lose money in all their third party transactions (Figure 9).

Their tight operating margins (Figure 10) and the fact that revenue is generally already directed at continuing or expanding patient care, mean that research should not distract health centers from their mission of providing care to the medically underserved and should help them leverage new resources that have a community benefit. Research activities must cover the costs of participation.





## Federal Investments to Expand the Health Center Program

Health centers enjoy broad bi-partisan support, given their unique and successful model of community-directed care. Congress established a Trust Fund under the Affordable Care Act (ACA) to accelerate health center growth to serve new communities and new patients through fiscal year 2015.

As health centers grow, they will serve larger numbers of the nation's most medically underserved and at-risk, reinforcing their role as the nation's largest national network of



primary care and national leaders in caring for those who are traditionally excluded from research. As witnessed by Massachusetts health centers after the Commonwealth passed health reform, the number of uninsured receiving care at Massachusetts health centers increased by 6% between 2007 and 2011. Meanwhile, the proportion of uninsured health center patients was more than 6 times the statewide average of uninsured.<sup>8</sup> Even though more people can be expected to become insured under the ACA, health centers can still expect to see high or even increasing numbers of uninsured patients, particularly in states that do not pass Medicaid expansion, leaving them fewer resources to allot to research.



## Key Resources for More Information:

- Bureau of Primary Health Care, Health Resources and Services Administration, HHS, "Health Center Program Requirements," <http://www.bphc.hrsa.gov/about/requirements/index.html>.
- Geiger J. The First Community Health Centers: A Model of Enduring Value. JACM. 2005; 28(4): 313 – 320.
- NACHC, *A Sketch of Community Health Centers: Chartbook*, 2013, <http://www.nachc.com/client//Chartbook2013.pdf>.
- NACHC 'Community Health Centers at a Glance,' Infographic, March 2012,



<http://www.nachc.com/client//Infographic-CHCs.pdf>.

- NACHC state fact sheets, <http://www.nachc.com/state-healthcare-data-list.cfm>
- NACHC, *Powering Health Communities: Community Health Centers Address the Social Determinants of Health*, August 2012 Issue Brief. <http://www.nachc.com/client/documents/SDOH1.pdf>
- NACHC's Weekly Washington Update: <http://www.nachc.com/washington-update.cfm>
- For more information and data on health centers, visit [www.NACHC.com/research](http://www.NACHC.com/research).

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<sup>1</sup> National Association of Community Health Centers. Health Centers in the Literature: Study Summaries. 2013. Accessed on February 2, 2013 at <http://www.nachc.com/literature-summaries.cfm>.

<sup>2</sup> US Department of Health and Human Services, Health Resources and Services Administration, Bureau of Primary Health Care. Medically Underserved Areas and Populations. Accessed October 30, 2013 at <http://bhpr.hrsa.gov/shortage/muaps/>.

<sup>3</sup> NACHC, 2013. Includes patients of federally-funded health centers, non-federally funded health centers, and expected patient growth for 2013.

<sup>4</sup> Agency for Healthcare Research and Quality. Priority Areas for National Action: Transforming Health Care Quality. National Academies Press: 2003. Edited by Karen Adams and Janet M. Corrigan, IOM Committee on Identifying Priority Areas for Quality Improvement, Healthy People 2020, Topics and Objectives. Accessed on November 1, 2013 at <http://www.healthypeople.gov/2020/topicsobjectives2020/default.aspx>.

<sup>5</sup> Jester, et al. 2013. National Survey of Health Centers' Research Participation: Activities and Needs. (forthcoming publication in CES4Health).

<sup>6</sup> Bureau of Primary Health Care Update. March 19, 2014 Presentation by Jim Macrae at the National Association of Community Health Centers Policies and Issues Conference.

<sup>7</sup> Section 330 under the Public Health Service Act.

<sup>8</sup> Ku L, Jones E, Shin P, Byrne FR, and Long SK. Safety-net providers after health reform: Lessons from Massachusetts. Arch Intern Med. 2011; 171(15):1379-84.

## MODULE 2: HEALTH CENTER RESEARCH EXPERIENCE AND NEEDS

### Building Off Quality Improvement Experience and Infrastructure

Health centers' program requirements and experiences have created the beginnings of an infrastructure that is already prime for research.

All health centers are required to engage in quality improvement (QI) and quality assurance activities. As of 2012, 90% of health centers have an Electronic Health Record System (EHR).<sup>1</sup>

Health centers, like primary care providers nationally, are working towards Patient Centered Medical Home (PCMH) recognition, with 73% participating in a PCMH initiative and 44% achieving PCMH recognition.<sup>2</sup> Most health centers already meet the basic domains of the PCMH<sup>3</sup> and as of August 2013, 29% of health centers achieved PCMH recognition for at least one of their delivery sites.<sup>4</sup>

Health centers also have partnerships and affiliations that can leverage this experience and infrastructure to engage in research. Many health centers participate in networks, such as Health Center Controlled Networks (HCCNs) and

Practice-Based Research Networks (PBRNs). HCCNs are collaborative business entities funded by HRSA that pool resources and bring infrastructure to scale across three or more independent health center organizations to improve quality and achieve cost efficiencies.<sup>5</sup> HCCNs are often responsible for centers' health information technology (HIT), including acquisition and use of EHRs, data management, network development and administration, and health information exchange. There are currently over 102 HCCNs, some of which are run by state health center associations. PBRNs are groups of primary care clinicians and organizations that engage in research to improve quality of care and health outcomes of their communities.<sup>6</sup> PBRNs allow providers to pool resources and data and to work collaboratively on common research interests that could benefit their communities.

These experiences and partnerships make up the platform by which health centers not only provide high-quality care, but also build research infrastructure and have a greater reach to disseminate and implement research findings.



### Health Center Research Experience, Roles Taken, and Gaps in Capacity

A recent national survey of health centers' research participation and activities<sup>7</sup> finds that more than half of health centers (56%) currently participate in research while more than two-thirds (69%) want to expand their research activities. Of the 44% who currently do not participate in research, 58% are interested in

getting involved. These results indicate that there is a strong interest at health centers to be involved in research (see Figure 11).

Despite the extent of health centers' involvement in research, less than 30% have staff whose specific duties include research

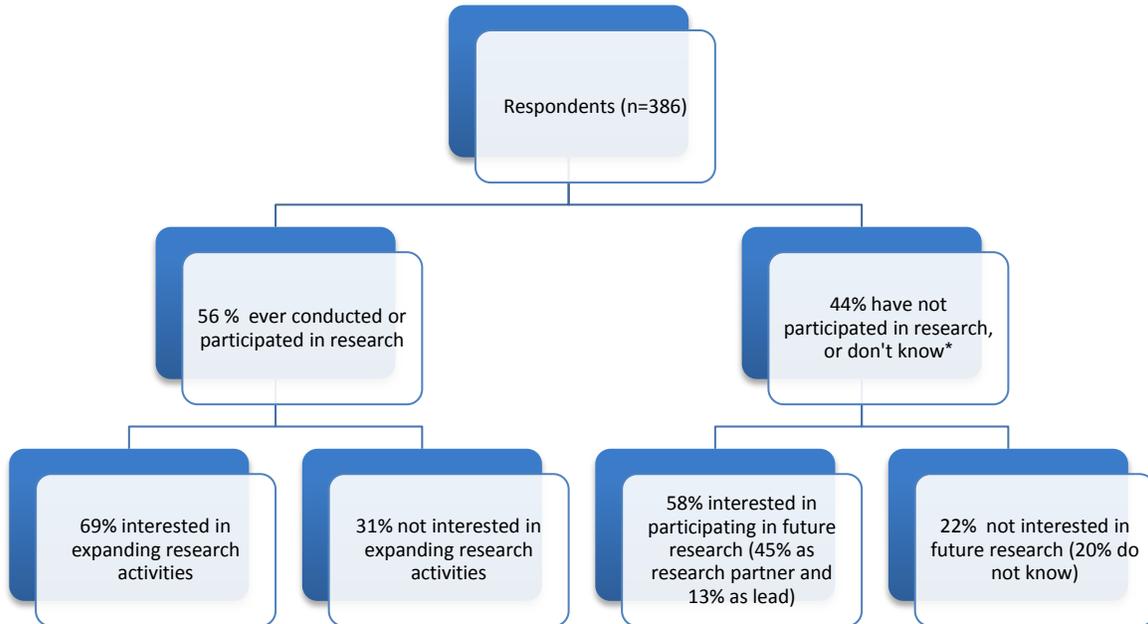
coordinating and conducting activities, while less than 40% have staff whose time is covered by research grants.

In fact, most health centers participate in research through partnerships with others (94%). Health centers have varied roles, but they mostly revolve around recruiting research participants, collecting data, and implementing the research intervention. They are not as involved nor have as much experience in developing research reports, managing research funding, conducting data analysis, and

interpreting findings. They seek to build and strengthen these skills, particularly in regards to finding and applying for funding opportunities as well as applying research to benefit not only their own clinical setting but also public policies.

**Individuals and institutions looking to partners with health centers should recognize that health centers vary greatly in their research experience, capacity, interests, and needs. The gaps in their research infrastructure and capacity should be discussed and addressed when building research partnerships.**

Figure 11



### Health Center Research Priorities

Health centers' research priorities are tied to everyday clinical practice and directed at narrowing health disparities. In fact, health

centers report that their top motivations for conducting research include reducing health disparities and improving the health of their patients through improved care delivery.<sup>8</sup> Many of these research interests are similar to

other practice-based settings. Health centers, like primary care providers nationally, are working to transform their care delivery models to meet new expectations for accountability.

Health centers are also interested in improving health outcomes for conditions commonly seen in their communities as well as nationally, such as diabetes, obesity, heart disease, asthma, and behavioral health conditions, as demonstrated by their participation in the HRSA-funded Health Disparities Collaborative, which aimed to improve care for people with chronic conditions through partnerships, care transformation, and evaluation.<sup>9</sup> Such conditions occur at higher rates at health centers compared to other practice settings.<sup>10</sup> Health centers also prioritize research that helps them achieve national criteria such as Patient Centered Medical Home and Meaningful Use recognition.

Despite these similarities, their mission-driven population health focus and comprehensive approach to care set them notably apart from mainstream primary care medicine. **Research questions must have direct and practical relevance to the health center, the larger health system, and community health.**



### **What Health Centers Hope to Gain from Research and Research Collaborations**

Health centers participate in research for many reasons. Most all health centers (91 – 92%) reported in a recent national survey that they participated in research to improve patient outcomes, reduce health disparities, and improve care delivery.<sup>12</sup> Ultimately, health centers engage in research in the hopes of creating new evidence-based practices and spreading generalizable knowledge while benefiting from research conducted with similar patients in similar settings, but they also

Accordingly, health centers' research interests center on translational research –research that transforms findings from basic science into practical applications that benefit health and clinical care.<sup>11</sup> Being knowledgeable on where evidence-practices currently lack, they are eager to identify, test, and spread proven interventions that narrow disparities, augment capacity, improve care experiences, and bend the cost curve. For example, health centers seek more effective means of:

- Addressing deep-rooted social determinants of health and aligning these programs with clinical care through Patient Centered Medical Homes;
- Integrating behavioral, dental, primary, and other care delivery within health centers;
- Creating seamless systems of care across provider settings for underserved and vulnerable populations;
- Removing barriers to essential preventive screenings to which underserved patients often have little access, such as cancer screening; and
- Preventing the onset of disease.



participate in research to gain tangible and intangible resources that come with research and research partnerships to build infrastructure and capacity.<sup>13</sup>

Tangible resources include funding, new staff, Health Information Technology (HIT) infrastructure, and patient education tools. Intangible resources include expertise from partnerships, staff training, opportunities to develop health professional training activities and partnerships, access to specialty care for patients, support for other health center

activities, such as Quality Improvement (QI) efforts or community needs assessments, and staff retention, particularly for staff that are eager to learn or eager to have diversified roles beyond their daily clinical or administrative responsibilities. For many health centers,

however, the tangible benefits of research are not always clear.<sup>14</sup> **Sharing resources, expertise, and staff also means that health centers do not have to divert limited resources from patient care while still advancing their research priorities.**



### **Barriers to Partnering with Health Centers and Ways to Navigate These Barriers**

Even though health centers have an infrastructure that provides a launchpad for research, they still face barriers to participating in research along factors such as resources, experiential know-how, time, and concerns. For example, even though most health centers use Electronic Health Records (EHR) to collect data on their patients, many do not know or have the staff time to be able to use EHR data for population management or research purposes. However, the issue is not just time. Clinicians are trained to think about individuals whereas researchers and population scientists think about groups and what happens on average in a group. Discussions between clinicians and researchers can help providers understand how they can use their data to better understand and manage their patient populations. Health center clinicians and other staff often need assistance generating their data in ways that demonstrate population level needs.

A recent national survey found that health centers' top reported barriers to participating in research were: the cost and care consequences of diverting staff from patient care, the lack of funding or ability to seek it, the lack of know-how in terms of publication, data analysis, participant recruitment, building a data infrastructure, and other concerns about where to begin.<sup>15</sup> Other studies pertaining to health center-based research have found similar barriers that can be categorized by

organizational, provider, and patient levels.<sup>16</sup> At the system level, substantial challenges include financial concerns, poor resource allocation, scheduling, inadequate reimbursement of services, and lack of buy-in from clinic leadership, and staff.<sup>17,18,19</sup> At the provider level, there are challenges around perceptions, demands, and lack of key skills and training.<sup>20,21,22</sup> And at the patient level, barriers exist along issues of mistrust, communication issues, and competing priorities.<sup>23</sup> While each of these challenges exists, it is also possible to structure research with a community orientation containing bi-directional interactions between researchers and practitioners to make these challenges opportunities for researchers to do important work and for practitioners to receive assistance.

Additionally, some health centers may prefer to use a community Institutional Review Board (IRB) or community research review process on top of an academic institution's IRB. Although this may require more work and lengthen the review time, it can provide a structural mechanism for enhancing "community-centered outcomes" and "patient-centered outcomes. Health centers could also request to have community partners as co-Principal Investigators to reflect the collaborative partnership and to acknowledge the community partner's contribution to the research project. Nearly a quarter (23%) of health centers make use of an independent IRB while 12% have their own internal review committee.<sup>24</sup> Therefore, it is important to know community and academic

IRB processes and the steps necessary to accommodate these preferences.

These barriers and concerns, in addition to health centers' unique structure and context, necessitate particular partnership models and methods of research engagement. Partnerships that are couched in the principles of community-engaged research can help overcome these barriers by valuing health centers and community members as equal partners, equitably sharing resources, becoming involved with the community, and committing resources to build health center research capacity.

Despite having a broad range of research interests to achieve their goals of improving health outcomes for medically underserved populations and reducing health disparities, many health centers have preferences for achieving these priorities.

As discussed previously, health centers have a great deal of experience with quality improvement (QI), and most have experience using the Plan, Do, Study, Act (PDSA) cycle of testing and implementing change. Their QI activities and federal program requirements, as well as their everyday clinical practice demands, mean that health centers require new information quickly. While their QI experiences position them to engage in research, for many health centers their experiences lie more comfortably in program evaluation. Academics can help health centers make this transition.

Relatedly, health centers often understand that collecting new data (such as Patient Reported Outcomes or data on patient risk factors) is critical for their performance improvement efforts, but measures of interest to researchers – both dependent and independent variables – may not mirror those of interest to health

centers, their board, their communities, or their patients. Multiple measures and multiple methods of collecting data may need to be incorporated into any one study so as not to miss any opportunities to understand the context of a research question. Using multiple measures and multiple methods of collecting data requires more work, but it presents an opportunity to interact with practitioners and find out why both partners have metrics, why they are important, and whether they represent what each partner intends.

Researchers, health centers, and patients often have different take-aways from research findings and different views regarding how those findings should be disseminated. For example, small but statistically significant magnitudes of effect may be of interest in an academic setting, but may not be meaningful to health center staff, communities, and patients. Or, health centers and academics may disagree on the point at which a measurable impact of an intervention is meaningful enough to keep an intervention going, especially if the intervention is highly prioritized by the community. Researchers should work with health centers in advance to come to an agreement for the best course of action for dissemination if there are unintended effects or unintended outcomes from the research.

Health centers also have concerns regarding Randomized Controlled Trials (RCTs) and Comparative Effectiveness Research and sometimes prefer observational studies. They fear that these types of studies could potentially disrupt patient care delivery and flow and also potentially fail to benefit their patients by denying a group (the control group) an improved medical product or delivery method. This stems from the role health

centers play in putting their patients' benefits first and foremost since many are often distrustful of research. There are ways to navigate these concerns, such as conducting cluster or phased randomization trials, cross-over designs that allow for delayed intervention, or by agreeing that the control intervention would be the standard of care rather than no care. Partnering with health centers presents an opportunity to explore study designs that best meet the needs of community partners.

Finally, health centers differ from other practice settings in many ways. They also vary greatly across sites. These differences need to be factored in to research design and interpretation of results and require spending time with the health center, its staff, and its patients to better understand its unique context and environment. However, even though health centers differ from other practice settings and even each other, they still provide applicable lessons to other health care settings, such as caring for people with co-morbid conditions, providing access to individuals seeking care, and operating in an environment of cost-containment yet high quality.



#### Key Resources for More Information:

- De las Nueces D, Hacker K, DiGirolamo A, Hicks LS. A systematic review of community-based participatory research to enhance clinical trials in racial and ethnic minority groups. 2012. Health Serv Res. 47(3): 1363 – 86.
- Shin P, Sharac J, Rosenbaum S, Paradise J. Quality of care in community health centers and factors associated with performance. Kaiser commission on Medicaid and the Uninsured Report #8447 (June 2013), available at <http://kff.org/medicaid/issue-brief/quality-of-care-in-community-health-centers-and-factors-associated-with-performance/>.

- Jester, et al. National Survey of Health Centers' Research Participation: Activities and Needs. (forthcoming publication in CES4Health).
- Beeson, et al. Engaging Community Health Centers in Research Partnerships: The Role of Prior Research Experience on Perceived Needs and Challenges. (forthcoming publication in Clinical and Translational Science).
- Shin, et al. Identifying Key Patient Demographics and Organizational Factors that Contribute to Health Center Participation in Research. (forthcoming publication in Journal for Ambulatory Care Management).
- [AAPCHO Community Criteria for Research Participation Fact Sheet](#)

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<sup>1</sup> US Department of Health and Human Services, Health Resources and Services Administration, Bureau of Primary Health Care. Uniform Data System. 2012.

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- <sup>2</sup> US Department of Health and Human Services, Health Resources and Services Administration, HRSA Patient-Centered Medical Home Initiative. Accessed on November 1, 2013 at <http://bphc.hrsa.gov/policiesregulations/policies/pal201101.html>.
- <sup>3</sup> Doty et al, 2010.
- <sup>4</sup> US Department of Health and Human Services, Health Resources and Services Administration, Bureau of Primary Health Care. Uniform Data System. 2012.
- <sup>5</sup> US Department of Health and Human Services, Health Resources and Services Administration, Health Information Technology and Quality Improvement. Accessed on November 1, 2013 at <http://www.hrsa.gov/healthit/toolbox/HealthITAdoptiontoolbox/OpportunitiesCollaboration/aboutccns.html>.
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- <sup>7</sup> Jester, et al. 2013.
- <sup>8</sup> Jester et al, 2013
- <sup>9</sup> Landon BE, Hicks LS, O'Malley AJ, et al. Improving the management of chronic disease at community health centers. *N Engl J Med*. 2007;356:921–934. Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. *Milbank Q*.1996;74:511–544. Wagner EH, Glasgow RE, Davis C, et al. Quality improvement in chronic illness care: a collaborative approach. *Jt Comm J Qual Improv*. 2001;27:63–80.
- <sup>10</sup> Dor A, Pylupchuck Y, Shin P, Rosenbaum S. Uninsured and Medicaid Patients' Access to Preventive Care: Comparison of Health Centers and Other Primary Care Providers. RCHN Community Health Foundation. 2008; Research Brief #4. Chin MH. (2010). Quality improvement implementation and disparities: the case of the Health Disparities Collaboratives. *Med Care*. 48(8): 668-675.
- <sup>11</sup> US Department of Health and Human Services, National Institutes of Health, National Center for Advancing Translational Sciences. 2013. Accessed on November 8, 2013 at <http://www.ncats.nih.gov/research/cts/cts.html>.
- <sup>12</sup> Jester et al., 2013.
- <sup>13</sup> Kwon S, Rideout C, Tseng W, Islam N, Cook WK, Ro M, & Trinh-Shevrin C. (2012). Developing the community empowered research training program: Building research capacity for community-initiated and community-driven research. *Progress in Community Health Partnerships: Research, Education, and Action*. 6(1); 43-52.
- <sup>14</sup> Michener L, Cook J, Ahmed SM, Yonas MA, Coyne-Beasley T, Aguilar-Gaxiola S. Aligning the goals of community-engaged research: why and how academic health centers can successfully engage with communities to improve health. *Academic Medicine*. 2012; 87(3):285-291.
- <sup>15</sup> Jester et al., 2013
- <sup>16</sup> Lemon SC, Zapka JG, Estabrook B, Benjamin E. Challenges to research in urban community health centers *Am J Pub Health*. 2006; 96(3): 1 – 3.
- <sup>17</sup> Riedy CA, et al. An FQHC research network in oral health: enhancing the workforce and reducing disparities. *Public Health Rep*. 2007 Sept-Oct; 122(5): 592-601.
- <sup>18</sup> Lemon SC, Zapka JG, Estabrook B, Benjamin E. Challenges to research in urban community health centers *Am J Pub Health*. 2006; 96(3): 1 – 3.
- <sup>19</sup> Riedy CA, et al. An FQHC research network in oral health: enhancing the workforce and reducing disparities. *Public Health Rep*. 2007 Sept-Oct; 122(5): 592-601.
- <sup>20</sup> Lemon SC, Zapka JG, Estabrook B, Benjamin E. Challenges to research in urban community health centers. *Am J Pub Health*. 2006; 96(3): 1- – 3.
- <sup>21</sup> Riedy CA, Ly KA, Ybarra V, Milgrom P.et al. An FQHC research network in oral health: enhancing the workforce and reducing disparities. *Public Health Rep*. 2007 Sept-Oct; 122(5): 592-601.
- <sup>22</sup> Daniels EC. Translation squared: improving asthma care for high-disparity populations through a safety net practice-based research network. *J Asthma*. 2005; Jul-Aug;42(6):499-505.
- <sup>23</sup> Lemon SC, Zapka JG, Estabrook B, Benjamin E. Challenges to research in urban community health centers. *Am J Pub Health*. 2006; 96(3): 1 – 3.
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## 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>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.

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<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.