

## 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

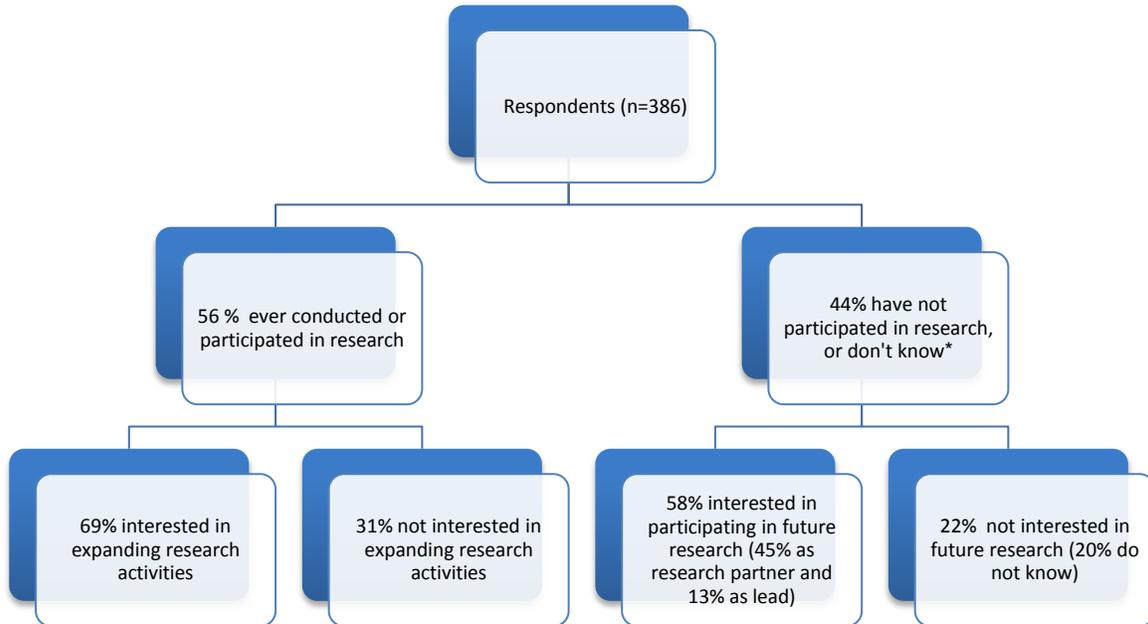
coordinating and conducting activities, while less than 40% have staff whose time is covered by research grants.

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



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>.
- <sup>6</sup> Agency for Healthcare Research and Quality. Practice-Based Research Networks (PBRNs). Accessed on November 1, 2013 at <http://pbrn.ahrq.gov/>.
- <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.
- <sup>24</sup> Jester et al., 2013