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).

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. Most health centers already meet the basic domains of the PCMH and as of August 2013, 29% of health centers achieved PCMH recognition for at least one of their delivery sites.

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. 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. 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 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 partner 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.

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. 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. Such conditions occur at higher rates at health centers compared to other practice settings. 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.

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. 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.

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. 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 participate in research to gain tangible and intangible resources that come with research and research partnerships to build infrastructure and capacity.

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.\textsuperscript{14} 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.

\textbf{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.\textsuperscript{15} Other studies pertaining to health center-based research have found similar barriers that can be categorized by organizational, provider, and patient levels.\textsuperscript{16} 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.\textsuperscript{17,18,19} At the provider level, there are challenges around perceptions, demands, and lack of key skills and training.\textsuperscript{20,21,22} And at the patient level, barriers exist along issues of mistrust, communication issues, and competing priorities.\textsuperscript{23} 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.\textsuperscript{24} 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 multiples 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, crossover 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.
- AAPCHO Community Criteria for Research Participation Fact Sheet

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


8 Jester et al, 2013


12 Jester et al., 2013


15 Jester et al., 2013


24 Jester et al., 2013