Innovation Networks for Improving Access and Quality Across the Healthcare Ecosystem

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Abstract

Partnerships between patient communities, healthcare providers, and academic researchers are key to stepping up the pace and public health impact of clinical and translational research supported by the National Institutes of Health. With emphasis shifting toward com-

munity engagement and faster translation of research advances into clinical practice, academic researchers have a vital stake in widening the use of health information technology systems and telehealth networks to support collaboration and innovation. However, limited interaction between academic institutions and healthcare providers hinders the ability to form and sustain the integrated networks that are needed to conduct meaningful community-engaged research that improves public health outcomes. Healthcare providers, especially those affiliated with smaller practices, will need sustainable infrastructure and real incentives to utilize such networks, as well as training and additional resources for ongoing technical assistance.

Key words: business administration/economics, distance learning, e-health, home health monitoring, policy

Innovation Networks

Federal agencies that support, deliver, and evaluate healthcare services, such as the Health Resources and Services Administration (HRSA), the Indian Health Service (IHS), the Departments of Veterans Affairs (VA) and Defense (DoD), and the Agency for Healthcare Research and Quality (AHRQ) play critical roles in the drive to improve access and quality by advancing the use of health information technology (IT), including telehealth services in rural, remote, and underserved urban areas. The IHS exemplifies the use of innovative technologies to address critical needs in resource-constrained environments. IHS and tribally operated health facilities have long used the Resource and Patient Management

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System (RPMS), a comprehensive software platform that helps streamline healthcare delivery and evaluate clinical processes and outcomes. The RPMS electronic health record (EHR) supports a wide variety of clinical functions with a customizable user interface that can accommodate different information and workflow needs, including those of researchers. RPMS also supports iCare, a population management software tool that gives providers and researchers the ability to create “virtual cohorts” of patients with common characteristics (e.g., age, diagnosis, community) and view patient and population data in customizable ways.¹

The IHS, in collaboration with National Institutes of Health (NIH), also supports innovative research partnerships through its Native American Research Centers for Health (NARCH) program, in which American Indian and Alaska Native (AI/AN) tribal organizations take the lead in formulating research questions and directing projects in collaboration with academic investigators.² This approach ensures that resources are distributed equitably among partners and that projects address questions of importance to tribal communities. For example, rheumatic diseases (e.g., arthritis) are over-represented in AI/AN populations. Supported in part by the NARCH program, clinician scientists in Oklahoma are discovering novel patterns of autoantibody markers in these populations, which may help improve diagnostic and prognostic accuracy and perhaps even point the way to better therapy. At the same time, they are helping tribes develop specialty clinics in rural areas to bring advanced rheumatology care to residents, using telehealth applications as “physician extenders,” transmitting laboratory and x-ray results, providing medication assistance program information, and holding Web-based videoconference training sessions for physicians across the state, facilitating collaborations throughout Oklahoma and as far away as the Alaska Native Medical Center in Anchorage.

As these examples illustrate, telehealth, encompassing the terms “health IT,” “e-health,” and “mobile health” as well as telemedicine, is a set of enabling tools and toolkits both for healthcare generally and for clinical and translational research and education. Exciting new “technology-enabled” service models are evolving for different specialty areas, such as expert triage via telehealth consultations. Research partnerships are crucial for assessing the feasibility and impact of telehealth technologies, and to compare, contrast, and analyze their ability to meet the needs of diverse communities. Providers also need to demonstrate sound business models for implementing these technologies, which tend to be disruptive, at least initially, and challenge established service models.

Linking science to practice ultimately hinges more on human relationships than on technology. New technologies must enable and

enhance relationships if they are to be effective and embraced, especially in chronic disease care management. Relationships built around high-priority research endeavors in primary care settings, e.g., implementation research and testing health promotion and disease prevention interventions, can lead to better relationships revolving around specialty care, including clinical trials for new therapeutic interventions. Such research must include a public health perspective, focusing on communities that are most vulnerable and most in need, making sure they are included and have access to the tools and relationships that NIH is trying to support and develop. This will require more shared dialogue across diverse translational communities, from researchers to clinicians, patients, families, and community organizations.

Telemental Health Research with Underserved Populations

In the mental health field as in other fields, practice often outpaces research. Many large health systems, for example the VA, the DoD, and several national health maintenance organizations, are rolling out telemental health services, primarily based on videoconferencing.³ There is a small but growing number of randomized controlled clinical trials (RCTs) showing efficacy of videoconferencing in mental health and equivalence with face-to-face treatment. A larger body of open trials, descriptive, and satisfaction studies exists describing the successful applications and implementation of this technology.⁴ There is a great need to evaluate telemental health services, prospectively if possible but retrospectively as well, so that services are optimized to better serve patients.

Although RCTs are often held as the “gold standard” for clinical research, it is unclear whether RCTs are always the most appropriate design for studies involving remote or underserved population. In many instances, the real world “standard-of-care” for comparison purposes is effectively the absence of care, due to the isolation of patients and lack of access to counseling and psychiatric services, making the selection of an appropriate comparison treatment in the design of an RCT challenging. Additionally, individual rural telemental health services often have relatively small numbers of patients, so in order to get sufficient numbers for larger effectiveness trials, it is often necessary to use multiple sites and consider studies across multiple systems. This adds to logistical challenges of undertaking such studies and underscores the need to strengthen infrastructure and provide incentives for collaboration.

More emphasis is needed on understanding how telehealth services can change models of care, shifting from hospital-based (emergency) care to more patient-centered home-based care. What types of mental

health interventions are well suited or poorly suited for telehealth approaches? What are the trade-offs between access and quality? Do telehealth services increase both quality and access, or does quality sometimes suffer, and if so, why is that the case? Can telehealth services be provided at lower cost than in-person services without sacrificing quality? Researchers must be open to selecting various types of methodologies to answer these questions, including qualitative methods and mixed methods as well as RCTs. Likewise, grant review panels for funding agencies need to understand and have an appreciation for mixed methodologies, particularly when reviewing proposals that involve marginalized and vulnerable populations.

More research is needed on models and processes for adapting telehealth tools and approaches to specific populations. Research in rural AI/AN communities poses unique conceptual requirements as well as logistical challenges. Investigators need to be aware of the history of mistrust and poor treatment of AI/AN peoples and be committed to engaging in long-term relationships with them. In addition to community expectations that research will address community needs and provide sustained benefits, projects typically involve multiple collaborators and institutional review boards, significant travel/transportation issues, and ongoing efforts to motivate participants to enroll and adhere to protocols. Good researchers serve as a medium between academia and communities, but there is a shortage of investigators who are well trained in this regard. Appropriately tailored research training programs supported by the NIH could make a major contribution here.

Role of Community Health Centers and Networks

HRSA supports a range of programs to improve healthcare access and quality for the nation's most vulnerable populations. Much of this work is accomplished through the funding of Community Health Centers (CHCs), comprising over 7,500 delivery sites. Also known as Federally Qualified Health Centers, these centers serve more than 20 million patients and may reach 30 million by 2015.⁵ CHCs are in the vanguard of healthcare innovation, leading the way, for example, in implementing the "medical home" model of care, aided in part by HRSA's investments in health IT. A recent survey conducted by the National Association of Community Health Centers showed that an increasing number of CHCs use EHR systems and a wide range of telehealth services.⁶

As CHCs seek to develop their telehealth capacity, recruiting a network of specialists poses a major and often the rate-limiting constraint. Regional telehealth networks supported through the Federal Communications Commission Rural Healthcare Pilot Program⁷ linking

rural providers to Academic Health Centers (AHCs) have tremendous potential to expand access to specialists, while at the same time bringing academic investigators and community clinicians together to accelerate innovation at the practice level. However, Medicaid reimbursement in many states hinders the sustainability of telehealth services in CHCs, and Medicare rules that do not allow payment for such services to patients in urban areas further discourages their increased use. In addition, a lack of telehealth infrastructure in specialist offices, a paucity of select specialists within AHCs approached to collaborate, and technical challenges to performing some types of examinations remotely (e.g., muscle and joint palpation hinder the ability of CHCs to offer telehealth services. While some of these issues fall outside the purview of NIH, they are nonetheless important to consider if federal funding and regulatory agencies hope to undertake a coordinated, comprehensive approach to evidence-based healthcare reform.

As part of their mission to improve community health through innovation, many CHCs are building research capacity to increase their ability to deliver cost-effective care and develop sustainable infrastructure for implementing effective health promotion and disease prevention interventions. Their location in underserved communities, engaged consumer advisory boards, culturally competent staff, team-based care models, and good working relationships with the populations they serve make CHCs prime settings for applied research to reduce and eliminate health disparities. For example, HRSA-funded Health Disparities Collaboratives⁸ and Health Center Controlled Networks (HCCNs)⁹ have successfully deployed IT tools to improve learning and the spread of healthcare practice change. HCCNs with sophisticated health IT capability make excellent potential partners for NIH-funded scientists, especially for research on clinical effectiveness and translation, dissemination, and implementation of new evidence-based interventions. Such partnerships could be a powerful force to advance our understanding of how telehealth applications can be effectively implemented in functionally isolated communities. Some CHCs are conducting research on their own but are ineligible to apply for NIH funding without an academic partner, which imposes significant limitations. CHCs want to partner with AHCs to gain access to research expertise and resources, but a major issue for CHCs is how to initiate and sustain effective and mutually beneficial partnerships. Potential academic collaborators need to recognize that improving patient care and health outcomes in the community is the research driver for CHCs.

Recommendations for NIH

1. Expand support for research to redesign care models for hard-pressed, well-described communities, focusing on how to

augment primary care with specialty expertise, then evaluate health outcomes.

- Expand research and development on store-and-forward applications beyond x-rays and other imaging modalities to include EHR data, laboratory data, patient interviews, telepsychiatry sessions, etc.
 - Explore the use of health avatars and virtual worlds.
2. Collaborate with DoD and other agencies to support research on systems science, e.g., how to close the loop between “Smartphone” handsets, patient Web-based personal health records, provider EHR systems, and regional health information exchanges.
 3. Foster true collaborative research models with underserved populations, models based on long-term relationships that ensure sensitivity to the various needs of multiple collaborators.
 4. Recognize community organizations as equal partners that bring valuable expertise and resources to the table, and share funding accordingly.
 - Expand programs that feature linked awards, such as the NIH Partners in Research initiative, in which community and academic partners receive equal amounts of funding to engage in collaborative projects.
 - Allow and encourage community organizations to apply for funding as primary awardees, with subawards to academic institutions, as in the IHS NARCH program.
 5. Build and support health research infrastructure in community settings, e.g., CHC networks and tribally operated health facilities.
 - Invest in people: research nurse coordinators, research subject advocates, clinical informaticians, and data analysts.
 - Invest in informatics: patient portals to facilitate recruitment and retention; disease registries; federated data repositories; appropriately managed data sharing and integration between clinical and research data systems.
 - In collaboration with existing healthcare systems, develop community-based core facilities that can integrate and facilitate both clinical care and research.
 - Ensure that funding is distributed equitably so that providers have the incentive and means to participate in research.
 6. Expand research on the effects of telehealth applications on human relationships, not only between patients and their providers but also between all members of the healthcare team (primary care physicians, specialty care providers, nurses, physician assistants, administrators, support staff, etc.).

Conclusions

At the core of NIH efforts to revitalize and transform clinical and translational research is the forging of new partnerships among organized patient communities, community-based healthcare providers, and academic researchers. With emphasis shifting, both for the NIH and the nation’s AHCs, toward meaningful community engagement and faster translation of research advances into clinical practice, academic researchers have a vital stake in widening the use of health IT systems and telehealth networks to support collaboration with community healthcare provider organizations. However, as shown by experience with practice-based research networks supported by AHRQ,¹⁰ participation of healthcare providers in academic research, whether it be clinical efficacy trials with new drugs and devices, comparative effectiveness research, or research on factors that influence implementation of evidence-based guidelines, will require a focus on research questions of importance to their patients, sustained investment in the necessary infrastructure in community settings where the work must be conducted, eligibility to apply directly to the NIH for research funding, and staff training and resources for ongoing technical assistance. NIH efforts to encourage AHCs to engage with community entities to develop collaborative research partnerships¹¹ and community health research infrastructure¹² will succeed only if resources are shared equitably with community partners so they have the incentive and wherewithal to collaborate on NIH-sponsored projects and programs.

Disclosure Statement

No competing financial interests exist.

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