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Learning Healthcare Systems
Office of the Director
Agency for Healthcare Research and Quality
5600 Fishers Lane
Rockville, MD 20857


To Whom It May Concern:

AcademyHealth, as the nonpartisan, professional home of nearly 4,000 health services researchers, policy analysts, and practitioners welcomes the opportunity to respond to the Request for Information (RFI) from the Agency for Healthcare Research and Quality (AHRQ) on learning healthcare systems. AcademyHealth represents both individuals and organizations, including health care delivery systems and others in learning health systems.

AcademyHealth is focused on supporting and accelerating the production and use of evidence and its application in the pursuit of safer, higher quality, and more accessible, equitable, and affordable health care. We believe that when health systems utilize the best evidence available to develop and reliably deploy evidence-based practices for both providers and patients we all benefit. To that end, we are also committed to ensuring sufficient and sustained support exists to inform decision making to improve health and health care, including professional development and training and funding for research through grants and contracts, as well as research dissemination, translation, and implementation.

Learning health systems require two-way integration between evidence creators and evidence users – essentially migrating from what has largely been a ‘supply-side’ orientation historically dominated by ‘evidence creators’ (a.k.a. researchers) to a more balanced and still evolving relationship between supply and demand. Demand can be expressed at the system (including community) and provider and patient levels, all of which represent current learning curves – and research priorities – for how to best capture needs.

Therefore, AcademyHealth fully supports AHRQ’s efforts to better understand the opportunities and challenges associated with building learning healthcare systems and the processes by which organizations develop, find, select, translate, and deploy evidence. As health and health care continue to evolve – with the steady rise of electronic health record (EHR) implementation and the consolidation of health care practices – we now, more than ever, have the potential to systematically create a virtuous cycle of health systems generating evidence and incorporating this and other evidence into the health care system itself, ultimately improving care delivery. For example, AcademyHealth partnered with AHRQ to launch the Electronic Data Methods (EDM) Forum to advance our understanding of EHR data limitations, to establish methods for
marshaling these data to conduct applied health services research, and to launch eGEMs, a peer-reviewed journal that supports shared learning in these areas.

The push for health care systems to move from volume to value has accelerated the pace and need for learning healthcare systems to provide better, more efficient care and improved health. This volume to value shift is a key, contemporary driver for ‘systemness’ and system-based learning to deliver such higher-value care. We know the right wheels are in motion, but a number of tactical, ethical, and implemental considerations complicate that transition.

**Utilization of Multiple Data Sources to Enhance Patient Engagement and Inclusion**

As new traditional and non-traditional data sources continue to surface, including patient-generated data, there will be an ongoing need to develop new research methods, governance structures, strategies for patient engagement and inclusion, and more effective approaches to use patient-reported measures in collaborative treatment planning. In a sense, health care systems will have to become ‘bigger’ and more systematic in terms of the amount and variety of data captured and will need to learn how to most effectively apply that data on a smaller scale consistently to patients – an area in which AHRQ could be a stimulus.

In considering the RFI question of “how are learning healthcare systems involving patients and families in their efforts,” it is important to think beyond more traditional engagement strategies that health systems have deployed (e.g. patient councils, etc.). Health systems are attempting to deliver the most tailored and valuable services possible by engaging patients prior to and at the point of care. However, systems are struggling to determine what successful, tailored patient involvement looks like across a number of levels, care settings, and communities.

To become true learning healthcare systems, systems will increasingly need to incorporate a holistic, patient-centered view, will need to capitalize on peer-to-peer learning, and – at a more overarching level – will need to determine how to tackle data-related barriers and challenges, including but not limited to data sharing and governance. The velocity of big data, needs for regulatory relief to share data across systems of care and community-based resources, and mechanisms to study complex interventions is a space in which AHRQ and AcademyHealth can collaborate to advance the science and supports needed for learning healthcare systems.

Currently, even for those health care providers who have access to records on individuals within some type of health information exchange, clinicians and caregivers see data only related to a patient’s health – merely a portion of an individual’s overall health. In the absence of ‘the full picture,’ with data from partners outside of the health care sector, health systems will not only fall short in their mission to provide the highest value care, but also in their mission to become operative learning healthcare systems. Additionally, as systems are pushed to be more accountable for their outcomes, not only are they being forced to rapidly engage in relationships with organizations that may have different cultures, but they are also grappling with the workflow, process, and governance issues associated with data sharing and integration.
For health systems to better understand and obtain a more accurate view of patients’ health, systems must look beyond the data on a person’s experience within the health system itself. Situational factors, such as whether a patient is homeless, is on food stamps, has behavioral health issues, or has been incarcerated, for example, all contribute to an individual’s state of overall wellbeing. For systems attempting to provide the highest quality care, systems must understand health care utilization and cost in addition to combining patient-reported information together with social determinant information to ensure the right care gets to the right person at the right time.

However, the science of measurement has not kept pace with these needs for supplemental information. Clinical team training on how to interpret and respond to such information will be critical as well, if care is to reflect and respect the values and preferences of both patients and clinicians and advance shared decision-making.

AHRQ could help bridge the divide between health systems and outside sectors in order to incorporate aspects on all social determinants of health, thereby ensuring a more comprehensive view of health. In this respect, we encourage AHRQ to engage and collaborate with new and existing programs. This includes continuing to collaborate with the Office of the National Coordinator (ONC), particularly on initiatives that seek to bridge data across sectors, such as the Community Health Peer Learning Program (see below), and with the National Institute on Minority Health and Health Disparities (NIMHD) on the development of innovative methods for evaluating complex interventions that balance rigor, timeliness, and relevance.

A systems perspective is needed to fully appreciate and address health problems created outside of health, including resource inequities and discriminatory practices. AcademyHealth urges AHRQ to continue investing in the development, testing, and dissemination of cutting-edge research methods, with a focus on the use of new and varied types of data and the methods and metrics used in quality improvement and research translation, dissemination, and implementation science to inform culturally competent patient engagement and inclusion strategies.

**Including a Focus on Practice-Based Evidence, Not Just Evidence-Based Practice**

To capitalize on how best to engage non-health sector partners and build upon the most promising innovations already in existence, AHRQ should create and enhance mechanisms through which systems can learn from and collaborate with peers in diverse contexts who are also working to develop innovative approaches to advance low-cost, high-quality care. Already familiar with facilitation and convening of stakeholders, AHRQ would be an appropriate player in this space as it seeks to support the move toward learning healthcare systems.

AcademyHealth has seen demonstrated time and time again the value generated through a peer learning approach. It is an effective mechanism for surfacing common challenges and generating practical solutions, thus reducing the time and efforts in local re-invention, and accelerating appropriate diffusion, adaptation, scale, and spread. Furthermore, communities of practice are usually more open to dissemination of information about innovative methods, practices, and measures following collaboration, rather than viewing each other as competitors.
As health care delivery organizations revolutionize their approach to care, health services research has a role to play in figuring out ways to scale their innovations in a way that benefits other systems. Integral to these spread and scale initiatives is an understanding of the balance between fidelity to the original intervention/strategy and appropriate adaptation to new contexts, an area where dissemination and implementation research can shed light and one which AHRQ should continue to support. An additional component worthy of AHRQ’s attention and investment is research to understand what is required for widespread sustainability of processes, practices, and overall systems of care.

Peer learning activities can directly support attention to many of the questions posed by AHRQ in the RFI, including:

- How are learning healthcare systems utilizing their own data to inform clinical and organizational improvements in healthcare delivery, design, and efficiency?
- Are learning healthcare systems using their own data to inform strategies to address population health and healthcare disparities?
- How do learning healthcare systems ensure that evidence either generated from their own data and/or adopted from external research is applied in a consistent manner throughout the organization, including across different specialties, levels of care, and clinical sites?
- What evidence, tools, training, methods, data, or measures could AHRQ develop or provide that would have a significant impact on the ability of health care delivery organizations to utilize their own data, use externally produced data and evidence, and meet their own quality and safety goals?

As mentioned above, as AHRQ considers how to participate in this space, the agency stands to gain tremendous insight from those who are already working to span health and non-health sectors, such as the aforementioned ONC-funded Community Health Peer Learning (CHP) Program, which works toward population health improvements by utilizing a peer learning collaborative. Specifically, program participants demonstrate how communities can link critical information within and outside of health care to address population health challenges ranging from pediatric asthma to housing insecurity. By revealing key themes and challenges, and offering technical assistance in areas such as data governance, community engagement, systems infrastructure, and sustainability, these community-based efforts have the potential to inform national strategy and align with other delivery system reform efforts driving toward better care, smarter spending, and healthier people.

While still in its early stages, the CHP Program has already shown promise with partners staying connected with one another to continue conversations and to take lessons learned by one system and apply it to their own. As we move toward a future state of health systems delivering more patient-centered care and delivering better outcomes (and getting paid for delivering better outcomes), there is much work that needs to be done to build and then reinforce these types of collaborations across systems and collaborative initiatives.
Additionally, AHRQ can build on its prior investments in learning networks like the EDM Forum to expand peer-to-peer learning networks that advance translation and implementation of best practices. Focused on learning health systems, the EDM Forum brought thought leaders, investigators, and stakeholder groups together to enhance understanding of the landscape of health research and quality improvement; incubate collaboration and innovation; and accelerate translation and dissemination. Its products, such as the open-access, peer-reviewed journal *eGEMs* and data sharing platform CIELO, pushed systems further in the direction of a true “open science” environment. These efforts promote the interoperability of systems needed to facilitate continuous learning and thus, improvement.

**Reengineering Processes to Reduce Low-Value Care**

The AHRQ RFI posed a number of questions about the role of metrics and data:

- What methodological and/or data quality issues have been encountered by the health care delivery organizations in generating evidence utilizing their own data?

- What metrics are learning healthcare systems utilizing to:
  - Understand the degree to which they are functioning as a system?
  - Monitor progress on their rate of moving clinical evidence into practice?
  - Evaluate the consistency of application of evidence across the organization?
  - How do these metrics relate to health care delivery organization goal setting, individual employee performance review and internal compensation linked to performance?

We are focusing our responses here on the too-often ignored dimension of low-value care. As health systems wrestle with the move from volume to value and the incorporation of a more patient-centered view of care, challenges at many levels surface: data, measurement, and interventions, and these involve financial, social, cultural, and policy dimensions.

Data to systematically identify low-value care across settings do not currently exist, in part due to the lack of research on this dimension of care as well as the absence of reliable, scientifically valid, and feasible measures of low-value care. One recent assessment of measures endorsed by the National Quality Forum found that only 3 percent addressed low-value care. AHRQ should work with the Centers for Medicare & Medicaid Services (CMS), the Veterans Administration (VA), the Patient-Centered Outcomes Research Institute (PCORI), and other agencies to support the development of additional low-value care measures, particularly those that can be used to inform clinician-patient interactions. As part of AHRQ’s work to advance low-value care measures, it would also be useful for AHRQ to assist in aligning measures across government and regulatory agencies to minimize burden and fully test measures in the field with learning healthcare systems prior to their implementation in government programs, such as the Merit-based Incentive Payment System (MIPS).
Essential to developing low-value care measures is to support further work to develop shared definitions of low-value care. As part of this, understanding the meaning of low-value care from diverse perspectives, including patients, providers and systems, is critical. Research on interventions to reduce low-value care has increased in recent years, but it is significantly behind research on interventions to promote the implementation of high-value care. In addition to sponsoring more research on such interventions, AHRQ should build on its partnerships with the NIH and the VA to understand de-implementation and sponsor the annual conference on the Science of Dissemination and Implementation in Health.

**Training the Next Generation of Evidence Producers and Users**

Finally, to ensure that future generations continue to build upon the progress made and trained in a manner that promotes continual learning and evidence-based improvements, AHRQ should continue to support training and professional development opportunities for both health services researchers and health care professionals to understand, evaluate, and test interventions in the health care system. AcademyHealth encourages AHRQ to build on its support of the recent Health Services Research Workforce Summit and work to implement the Summit recommendations, in partnership with other funders of health services research and AcademyHealth.

AcademyHealth also encourages AHRQ to look to models like the Delivery System Science Fellowship, which pairs doctorally prepared researchers with some of the nation’s leading delivery systems for hands-on training to enhance and apply analytic skills to relevant and timely research topics within a mentoring environment. In placing these emerging independent researchers with delivery system leaders throughout the country, the Fellowship increases the capacity of the health services research workforce. Another model is the recently launched National Cancer Institute (NCI) Health Care Delivery Research Visiting Scholars Program, which seeks to provide mid-career scientists working in the field of health services or health care delivery research, with the opportunity to collaborate with the NCI to advance knowledge to improve cancer care. Embedding health services researchers into the delivery system workforce is a penultimate step in becoming a mature learning healthcare system as envisioned in *Crossing the Quality Chasm*.

Beyond researchers, AHRQ should explore how to incorporate other healthcare professionals into the learning healthcare system evolution – those on the ‘front lines’ day in and day out – who are best able to identify needs and help direct approaches. Consulting the National Academy of Medicine’s Roundtable on Evidence-Based Medicine’s Learning Healthcare System Workshop Summary, opportunities for training health professionals may include “developing tools and systems that embed evidence into practice workflow, reshaping formal educational curricula for all healthcare practitioners, and shifting to continuing educational approaches that are integrated with care delivery and occur each day as a part of practice.”

Given AHRQ’s mission and federal charge to conduct health services research, designating space for learning healthcare systems within its portfolio is both appropriate and relevant. AHRQ is uniquely positioned to guide health systems not only in the gathering and supplying of the
most promising evidence-based practices, but also in the areas of peer-to-peer learning, training, and cutting-edge research methods. We look forward to seeing how AHRQ leverages its past and present opportunities to support this transformation.

Thank you for the opportunity to submit these comments. We look forward to working with you as you consider possible roles and opportunities in this environmental shift toward learning healthcare systems.

Sincerely,

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