

April 3, 2015

Karen B. DeSalvo, M.D., M.P.H., M.S. National Coordinator for Health Information Technology U.S. Department of Health and Human Services 200 Independence Avenue, SW, Suite 729-D Washington, D.C. 20201

Re: Response to *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap, Draft Version 1.0*

Dear Dr. DeSalvo:

AcademyHealth welcomes the opportunity to provide input to the Office of the National Coordinator for Health Information Technology (ONC) on its *Shared Nationwide Interoperability Roadmap, Draft Version 1.0.* We are the professional home of more than 5,000 health services researchers, policy analysts, and practitioners, whose work helps us understand and improve our complex health system and the information infrastructure that supports it, thus enabling better health outcomes for more people at greater value.

The Interoperability Roadmap is in and of itself a positive indicator that ONC is reaching out to a broad array of stakeholders to define the responsibilities of government, industry, the provider and payer communities, researchers, developers, and others in achieving interoperable systems that support personcentered care. AcademyHealth strongly believes in ONC's commitment to identifying innovative ideas and promising practices that will help achieve interoperability and benefit patients and society at large by making the right information available to the right people at the right time.

As the Interoperability Roadmap goes through revisions, we urge ONC to prioritize a few key, overarching goals and reduce the organizational complexity of the document so readers will have an intuitive grasp of what 'interoperability' truly means and how it will be achieved. We believe it is vitally important to make the Roadmap easily understandable by non-technical audiences, both to help unify the field and to help increase innovation in support of this work. A positive first step in the revision could be to harmonize and streamline the "guiding principles," "building blocks," and "critical pathways" within the Roadmap, which would allow ONC to better communicate overarching goals as well as to develop an infographic to illustrate them.

AcademyHealth, though encouraged by several provisions within this draft document, would urge ONC in future iterations of the document to place more emphasis on the critical role of the research community as an essential component of a learning health system, whether that relates to secondary use or to reuse of clinical data for research. In order for health information technology (HIT), including electronic health records (EHRs), to make an impact, data must be analyzed and understood so that delivery of care can be improved. Therefore, we appreciated the following points made within the document:

• Inclusion of "people and organizations that generate new knowledge" among the identified stakeholders.

AcademyHealth supports the efficient flow of clinical information for authorized reuse by the research community and works to improve the infrastructure and ecosystem needed for the dissemination and uptake of evidence-based findings by the health care system. To that end, we encourage ONC to consider policies that enhance—and do not unnecessarily restrict—the quality, availability, timeliness, and affordability of data and tools used to conduct and disseminate research.

Along those same lines, as ONC weighs the prioritization of use cases, AcademyHealth recommends supporting a governance framework that gives researchers appropriate access to identified and de-identified clinical and claims data for the production of robust, meaningful research and focuses on the role of patients in their own care—including facilitating access to their data for self-management and care across systems and settings (i.e., Appendix H use cases 2,19, 21, 56) and exchange of data among providers (i.e.,17), as well as promoting opportunities to participate in research—in addition to those cases that provide continued support for public and population health (i.e., 1, 4, 50, 51), measuring and reporting on care to improve quality and value (i.e., 10, 38), and facilitating discovery (i.e., 15, 16).

• The call to action for providers to leverage data beyond their internal systems for clinical research, quality improvement, and population health analytics.

AcademyHealth supports enhancing the evidence base and moving knowledge into action. We value ONC's inclusion of calls to action (Table 4, pp. 53-54) for providers to collaborate more fully with research institutions, public health departments, and other partners to generate new knowledge that helps to fulfill the Triple Aim by recognizing the importance of research to improve health care and care delivery.

There are many promising examples of continuously learning health systems that are improving care while contributing new methods and approaches to facilitate meaningful interoperability. AHRQ-funded research networks such as Improve Care Now, CERTAIN, the Indiana Registry, and SAFTInet, in addition to ONC Beacon Communities in Michigan, Minnesota, and New Orleans offer a subset of relevant examples. All offer live demonstrations of systems working towards interoperability that can contribute new knowledge on critical health issues such as Crohn's disease, surgical outcomes, dementia care, and pediatric asthma, among others. Similarly, AcademyHealth's peer-reviewed, open access journal, *eGEMs*, was created with support from AHRQ for the express purpose of highlighting lessons learned from quality improvement and research efforts that promote the interoperability of systems needed to facilitate continuous learning and improvement.

• The call to action for public and private stakeholders to establish a single coordinated governance framework and process.

The Roadmap rightly views the HIT ecosystem as a learning health system (LHS) and considers rules of engagement and governance as a fundamental building block for LHSs of the future. Of particular concern to the research community is the need for coordinated governance to facilitate data-sharing

agreements among different institutions, including the need to agree on legal, policy, and procedural issues. Without these agreements, there are significant delays and many missed opportunities for collaboration. AcademyHealth is excited to see ONC define a need for public-private collaboration around shared governance (Table 1).

We encourage ONC to consider adaptation and support for partnership models that facilitate learning, collaboration, and sharing of successful governance models among researchers and other stakeholders to build learning health systems that improve patient care and outcomes. Such forums can broaden awareness and agreement among existing communities with the goal of coordinating governance processes.

Person-centered care, with information flowing to the right person at the right time, is a goal of the nation's health reform efforts. Currently, most health systems are unable to integrate clinical data from different providers and settings to coordinate and improve the quality of care, and consumers are not able to access their own clinical information or to generate personal health information that can be integrated with their clinicians' EHRs. Much remains to be done.

Effective communication of progress toward interoperability is critical to build support and promote understanding among policymakers and the general public. We encourage ONC to make it a priority to communicate clearly about the steps necessary to achieve interoperability for the future and to set achievable goals or "near-term wins," as described in the Roadmap.

In sum, even with the best intentions for public-private collaboration around governance, the Roadmap will fall short of its potential if it doesn't communicate clearly to all stakeholders.

We look forward to working with ONC to determine how to best integrate the health services and implementation research communities into the Interoperability Roadmap deliberations. We believe that our experience with governance through the EDM Forum may provide a model for ONC's consideration. If you have any questions about these comments, please don't hesitate to contact Dr. Lisa Simpson, President & CEO of AcademyHealth at 202.292.6747 or <u>lisa.simpson@academyhealth.org</u>.