



June 28, 2017

Dr. Bryan Biegel
Director, National Coordination Office
Networking and Information Technology Research and Development
4121 Wilson Boulevard
Arlington, VA 22230

Submitted electronically at: hitrdframework2017@nitrd.gov

RE: Request for Comment – Draft Federal Health Information Technology Research and Development Strategic Framework

Dr. Biegel:

The American Medical Informatics Association (AMIA) is pleased to provide input on the Draft Federal Health Information Technology Research and Development Strategic Framework. We appreciate the Health Information Technology Research and Development Interagency Working Group's (HITRD IWG) efforts to develop this request for comment (RFC) on the draft R&D Framework.

AMIA is the professional home for more than 5,400 informatics professionals, representing front-line clinicians, researchers, educators and public health experts who bring meaning to data, manage information and generate new knowledge across the health and health care enterprise. As the voice of the nation's biomedical and health informatics professionals, AMIA plays a leading role in advancing health and wellness by moving basic research findings from bench to bedside, and evaluating interventions, innovations, and public policy across settings and patient populations.

AMIA strongly supports the R&D Framework developed by the HITRD WG, including its primary motivators, cross-cutting health IT R&D needs, and collaboration opportunities. The vision outlined in the opening paragraphs of the Framework underscores the tremendous opportunity we have to improve the lives of all Americans through development of health IT and health informatics. Below, we offer recommendations for consideration as the HITRD IWG develops its final R&D Framework. However, we first wish to make a point of clarification.

The Framework omits the term "informatics," thus overlooking the founding discipline responsible for health IT research and development. Health informatics is the 50-years-plus branch of study concerned with data collection, analysis, and application within broad domains of health, including healthcare delivery, public health, consumer health, clinical research, and translational research. Health IT encompasses a set of ever-evolving information and communication technology tools, largely focused on technological infrastructure, and unconcerned with the underlying clinical

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concepts that will enable this Framework’s vision to become reality. While we can appreciate that health IT and health informatics are terms used interchangeably, we recommend the final version of this R&D Framework include the term informatics appropriately. Further, we recommend federal officials consider the deep and rich scholarship contained in the [*Journal of the American Medical Informatics Association*](#) and [*Applied Clinical Informatics*](#) as it proceeds with the implementation of this Framework.

Motivators of Health IT Research and Development

The R&D Framework outlines nine areas of key goals for national health. We recommend the HITRD IWG consider the following AMIA observations and recommendations:

1. Using data to improve the safety, reliability, and quality of healthcare is paramount

Section 2.5 represents one of the most important areas for federal R&D. Funding efforts meant to make sense of the oncoming deluge of data¹ in the service of care delivery and wellness represents one of the largest opportunities faced by the federal government. Of particular importance is sustained and increased support for new and novel kinds of clinical decision support. AMIA foresees a near-term need to transition smaller CDS demonstrations to larger scale projects. Federal leadership in this capacity will be essential.

2. Interoperability testing is a prerequisite for interoperable systems

Section 2.6 includes the sentence, “To motivate and provide the technical imperative to achieve interoperable care coordination, bidirectional data sharing and testing should be a mandatory aspect of programs that regulate care providers. This interoperability standard is already required by law for the Department of Defense (DoD) and the VA.”² AMIA strongly agrees with the statement, yet little progress has been made to ensure that health IT systems certified to federal requirements are tested for interoperability. While we acknowledge that true interoperability testing would be difficult, we urge federal agencies to prioritize R&D in this area to achieve widespread interoperability, inside and outside the DoD and VA.

3. Federal agencies must support basic, applied and advanced informatics training³

AMIA strongly encourages federal agencies to understand their duty to support a modern, 21st century healthcare workforce, as outlined in 2.8. AMIA believes a three-pronged approach is needed to educate and train a modern healthcare workforce, including:

- Basic “informatics literacy” for all health professionals that is part of medical education, biomedical research, and public health training to give clinicians the skills needed to collect and analyze information and apply it in their practice;
- Intensive applied informatics training to improve leadership and expertise in applying informatics principles to healthcare problems; and
- Support for education professionals who will advance the science and train the next generation of informatics professionals in this developing and dynamic field of study.

¹ Such as EHRs, the IoT, new kinds of medical devices (including SaaS), environmental, and genomic data

² Review of Military Health System Modernization Study, Pub. Law No. 113-66, Sec. 713 (2015)

³ Perlin, J., Baker D., et al. “Information Technology Interoperability and Use for Better Care and Evidence: A Vital Direction for Health and Health Care,” National Academy of Medicine. September 19, 2016

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4. Policy development, in addition to technology development, is needed for systems

As outlined in 2.9, data generated by a host of other systems, including laboratory, imaging, consumer mHealth, and medical devices “have the potential to transform health.” These systems are either governed by different programs/policies or are not regulated at all, in the case of mHealth. AMIA recommends policy development, as well as technology development, is needed to see this objective area come to fruition.

Cross-Cutting Health IT R&D Needs

AMIA largely supports the areas identified, as well as the descriptions and outcomes described in this section. We underscore the need for R&D in three distinct areas that are aligned with existing categories: **development of granular data specifications** (*standards and terminology area*), **true interoperability testing** (*interoperability and implementation guidance area*), and a **“digital, computable print all” functionality for improved data portability** (*accessibility, generalizable use cases, infrastructure for sharing areas*).

First, we urge a focus on development of granular data specifications, which will enable a “periodic table of elements,” approach to biomedical data standards. We lack a formalized approach to combine discrete data elements for specific use cases – e.g. quality measurement. To facilitate data re-use and interoperability, federal agencies should work with stakeholders to develop granular data specifications, including metadata, and standards to support research for use in the federal health IT certification program.

Second, we reiterate our call for true interoperability testing, not just conformance testing, for health IT modules certified to federal requirements. Interoperability testing ensures that systems can not only send data using a specified standard, but that a system can receive numerous variations on a standard. We refer you to Postel’s Robustness Principle, which is to construct a system capable of being conservative in what it sends, but liberal in what it accepts from other systems.⁴

Third, we anticipate that data portability, which receives no mention in this document, is of cross-cutting concern. Were EHRs, for example, able to provide full digital exports that maintained computability for all patients who ask for them, then we expect a dramatic proliferation of tools and applications would arise to help patients utilize their data. This has not occurred because patients do not have a “digital, computable print all button” they can push to get structured and unstructured data from their record. Likewise, clinicians complain about the usability of their systems, but they are unable to export their patient data from one system and import it into another without tremendous cost – indeed, they will likely never get all the data from one system to another, but only summary records. This may be a narrow area of focus, but the state of data portability is surely a concern across the health ecosystem.

Collaboration Opportunities in Health IT R&D

AMIA appreciates the R&D Framework’s incorporation of this section, as we see it akin to a strategy to implement. We are especially supportive of federal efforts to engage in joint / collaborative solicitations, and we see Other Transaction Authority as being tremendously useful

⁴ Postel, Jon, ed. (January 1980). Transmission Control Protocol. IETF. RFC 761. <https://tools.ietf.org/html/rfc761>

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with proper oversight. AMIA stands ready to assist in the implementation of this Framework in whatever way we, and our members, can be helpful.

Current Investments in Cross-Cutting HIT R&D

We see this as an incredibly valuable output of the R&D Framework, and could help funders develop a portfolio approach to managing research – especially if/as additional dimensions are added, such as relative risk and costs of specific projects. One consideration HITRD IWG may consider, is development of an Appendix to elaborate on the current R&D investments made by the agencies listed. For instance, there are several big projects at smaller NIH ICs, such as NCATS, that could be listed here and could aid in understanding where gaps exist. While we appreciate that this could be a daunting task, perhaps a way to begin would be identification of those projects that can be highlighted as exemplary for being collaborative and cross-cutting.

We appreciate HITRD IWG’s work in this important area, and we are excited about the possibilities this new paradigm will have for bringing new and innovative therapies to American consumers. We look forward to working closely with NITRD and the HITRD IWG to bring the expertise of health informatics professionals to our exciting and shifting paradigm for health and healthcare.

Thank you for considering our comments. Should you have questions about these comments or require additional information, please contact Jeffery Smith, Vice President of Public Policy at jsmith@amia.org or (301) 657-1291. We look forward to continued partnership and dialogue.

Sincerely,



Douglas B. Fridsma, MD, PhD, FACP, FACMI
President and CEO
AMIA