March 18, 2020



Don Rucker, M.D. National Coordinator for Health Information Technology Office of the National Coordinator for Health Information Technology U.S. Department of Health and Human Services 330 C Street, SW Washington, DC 20201

Re: Draft 2020-2025 Federal Health IT Strategic Plan

Dear Dr. Rucker:

This letter provides the comments of the Mount Sinai Health System that you requested on the draft 2020-2025 *Federal Health IT Strategic Plan* issued by your Office on behalf of the Department of Health and Human Services. We very much appreciate the opportunity to provide comments on the plan. We serve as Chief Medical Information Officer and Chief Data Officer of the Mount Sinai Health System and have already put the draft plan to use building greater consensus about the future our own IT and data strategy in the course of preparing these comments.

The Mount Sinai Health System is New York City's largest academic medical system, encompassing eight hospitals, a leading medical school, and a vast network of ambulatory practices throughout the greater New York region. Mount Sinai is a national and international source of unrivaled education, translational research and discovery, and collaborative clinical leadership ensuring that we deliver the highest quality care—from prevention to treatment of the most serious and complex human diseases. The Health System includes more than 7,200 physicians and features a robust and continually expanding network of multispecialty services, including more than 400 ambulatory practice locations throughout the five boroughs of New York City, Westchester, and Long Island. The Mount Sinai Hospital is ranked No. 14 on *U.S. News & World Report*'s "Honor Roll" of the Top 20 Best Hospitals in the country and the Icahn School of Medicine as one of the Top 20 Best Medical Schools in country. Mount Sinai Health System hospitals are consistently ranked regionally by specialty and our physicians are in the top 1% of all physicians nationally by *U.S. News & World Report*.

As an academic medical center and school of medicine fully embedded in a large urban health system, Mount Sinai is uniquely positioned to work at the intersection of research and clinical care and translate between the two. This applies to Health IT and biomedical informatics just as it does to all areas of translational research, and we have worked to exploit this opportunity in several ways, including, for example, putting Mount Sinai at the vanguard of the open notes movement in New York State and introducing a pathogen surveillance program that combines academic skills in genomics and bioinformatics with hospital infection prevention and operations across our health system. This opportunity and our experience with the difficulty and benefits of actually translating good science to effective practice in IT-heavy disciplines informs our comments.

In general, we could not be more supportive of the 2020-2025 Federal Health IT Strategic Plan. We feel that it hits all the important points in an integrated and clear way that will provide strong guidance and direction to the government and the nation. It is obviously a strategy, and the details of how these goals are to be achieved will be spelled out in future more detailed and focused efforts. We look forward to working with you and other partners in the health care ecosystem to advance those focused efforts. With that in mind we offer the following points that you may consider emphasizing more strongly and explicitly in the *Plan* because we believe that they will be essential to progress.

- **1. Cybersecurity.** Effective cybersecurity is an essential foundation for any of this working. It is a significant concern for patients and all parties in the health care ecosystem and a substantial drain on budgets and attention in most organizations.
- 2. Provenance. Knowing the original source of data, it's transformations, and any restrictions on its use is crucial to the eventual correct understanding of that data. This is likely even more true as we attempt to integrate more data collected outside the health care delivery organizations such as social determinates of health, geocoded information, and data from patient apps into patient care, as described in Goal 3 of the *Plan*. Embracing some of the rigor of FAIR guidelines in the Health IT ecosystem, for instance, could help, along with continued focus on standards that track provenance.
- **3.** Universal Patient ID. Few patients get all their care with a single provider and it will always be messy and error prone to match patients without a single identifier that spans the nation. This has always been a severe problem that degrades care, but it is worth noting that it is causing major problems for us right now today with COVID-19 response. That's unacceptable in the 21<sup>st</sup> century.
- 4. Patient Empowerment. There is a lot in the *Plan* about getting data from providers to patients. This is appropriate because information blocking is real today and needs to stop. Patient control of their complete medical records is something we could not support more strongly. Because Mount Sinai is 100% committed to using all available information from the literature, from diagnostics, and from patients themselves to provide the highest-value evidence-based medical care we can, patient control of their complete medical records can only help our patient care mission if they trust us enough to share their complete medical record from all providers with us. Similarly, because our commitment to research, innovation, and education is grounded in excellent and evidence-based medicine, this helps everything we do. There are several subpoints to this we feel deserve emphasis:
  - a. Moving patient data to providers. The *Plan* emphasizes getting data to patients. We need to be careful that we don't burden the patients excessively and also make it just as simple to move data between providers to support patient care, even if patients are themselves not interested in
    - careful that we don't burden the patients excessively and also make it just as simple to move data between providers to support patient care, even if patients are themselves not interested in reviewing or having a copy of their data. Not all patients wish to be active participants in management of their data.
  - **b.** Ensuring consistent protections for patient data in all settings. Right now a patient taking health information from their medical records is not assured the same HIPPA protections for those data if they are given to another company. The health care ecosystem the *Plan* envisions will not work well without consistent handling of patient data wherever it travels.
  - **c. Consent.** Streamlined, clear, universal consents for research would improve the patient experience and increase participation in research. Standard consents should be developed and promulgated, and a mechanism to re-contact patients to get explicit consent for protocol extensions needs to be put in place.
  - **d. Dual use of medical information for research and clinical care.** In Objective 4b: Establish transparent expectations for data sharing, there needs to be acknowledgement that these shared data are valuable for research and that mechanisms for their facile, consented use need to be developed. With more and more data in electronic formats, our obligation to mine data to improve the quality or care cannot be met without access to all data, including shared data, and unless these shared data are accessible for Research, no-one can publish this important quality work and gain the societal benefits of peer review and broad communication of results.

On behalf of the Mount Sinai Health System, we thank you for putting together this comprehensive draft 2020-2025 *Federal Health IT Strategic Plan* and look forward to partnering with you and others to progressing this important work between now and 2025.

Sincerely,

Bruce Darrow, MD, PhD Chief Medical Information Officer Senior Vice President Mount Sinai Health System

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Andrew Kasarskis, PhD Chief Data Officer Executive Vice President Mount Sinai Health System