

SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

Better outcomes through better diagnosis.

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Dear Dr. Rucker:

On behalf of the leadership and members of the Society to Improve Diagnosis in Medicine (SIDM), we appreciate the opportunity to comment in response to ONC's work on identity and patient matching. SIDM is a 501(c)3 organization founded to catalyze and lead change to eliminate harm from diagnostic error, in partnership with a large Coalition of the nation's premier health care systems, specialty societies, patient advocacy groups, certifying and accrediting organizations, risk management organizations and others that together represent hundreds of thousands of healthcare providers and patients. Here, we want strongly to underscore the critical importance of accurate patient matching specifically to diagnostic quality and safety.

Diagnostic error is the leading cause -- by far -- of serious iatrogenic harm in the U.S, responsible for as many as 80,000 premature hospital deaths each year and affecting 1 in 20 ambulatory patients, sometimes with devastating consequences. Getting to an accurate diagnosis is often a complex, longitudinal process with many inputs and many potential failure points. A chief contributor to diagnostic error is failure to accurately link pieces of a patient's diagnostic journey to that patient: medical liability databases are too full of stories of test and consultation results returned to the wrong patient chart, even within the same institution and EHR. A reliable and automated

patient identity system that spans the diagnostic continuum potentially could eliminate such failures.

False positives and false negatives in current matching efforts also contribute to diagnostic error. In the case of false positives, where records of two different patients are linked, the potential for misdiagnosis is obvious. Moreover, the incorrect data can cascade to a multitude of internal and external systems and databases such as laboratory, radiology and health information networks, creating lasting potential for serious harm. In the case of a false negative match, the diagnosing clinician may not have access to critical information such as co-morbidities, an accurate problem list, laboratory and imaging studies and medications – information often critical to formulating a working diagnosis. As a result, duplicative studies and tests may be ordered, adding costs to both the patient and the system. In both scenarios, diagnosis, and subsequently care decisions, are based on an erroneous or incomplete picture of the patient's medical history.

We also wish to emphasize the longitudinal aspect of the diagnostic process, especially for rare or complex conditions. It is often said that the best diagnostic tool is "time", meaning monitoring the evolution of a disease process along with investigative tests. For this, a reliable, linked longitudinal patient record is crucial. Take, for example, the diagnosis of Systemic Lupus Erythematosus. Diagnosis based on Systemic Lupus Collaborating Clinics Criteria (SLICC) requires a subset of 11 relatively non-specific symptoms (ex. joint pain, oral ulcers, rash) and lab data. In Chicago, for example, patient care fragmentation is high due to provider availability, changes in insurance due to job changes, and a high density of competing health systems. A physical therapist may treat the joint pain, a dermatologist assesses the rash, bloodwork at a separate hospital shows anemia, and a nephrologist takes care of the kidney disease. It is no surprise then that the average time to diagnosis for lupus is six years (https://www.lupus.org/resources/lupus-facts-and-statistics). A reliable patient identification/matching system would help connect these dots as the patient passes through these distributed sites of care.

Another setting of high care fragmentation, and where timely diagnosis is of utmost importance is the Emergency Department. Many patients arrive confused or comatose, with or without identification. A hyphen in the last name, or mistyped keystroke when entering birthdate creates an entirely new patient record, losing any insights from prior hospitalizations or clinic visits. Prior studies have shown the benefit of Health Information Exchanges on faster and improved care in the Emergency Department, however HIEs are dependent on accurate patient matching.ⁱⁱ

Lastly, there is no greater imperative for robust patient identification and matching than the COVID-19 pandemic. Accurate identification of patients and properly linking them to their data is one of the most difficult operational issues during a public health emergency. Field hospitals and temporary testing sites intensify these challenges. There are many reports, especially from the early days of the pandemic, of physicians defaulting to a Covid diagnosis when in fact other disease processes, documented in an unavailable medical record, were responsible for Covid-mimicking symptoms. Laboratories have reported difficulties returning COVID-19 results to the correct patients because of lack of comprehensive patient demographic data. Many states and counties are stymied by basic information mistakes such as an old home address or, as mentioned above, last names spelled with or without a hyphen. Clearly, more sophisticated and reliable identification and matching mechanisms are needed. Finally, given what we are learning about potential Covid sequalae, ensuring that the correct patient medical history is accurately matched to the patient is critical to inform future diagnoses and for tracking the long-term effects of Covid-19.

Thank you again for the opportunity to comment on this important work through the lens of diagnostic quality and safety.

Sincerely,

Paul Epner, CEO

Society to Improve Diagnosis in Medicine.

ⁱ Diagnosis of Lupus - care fragmentation - https://onlinelibrary.wiley.com/doi/full/10.1002/acr.23161 SLICC Criteria in EHR data - https://lupus.bmj.com/content/5/Suppl_2/A18.1

[&]quot; - https://pubmed.ncbi.nlm.nih.gov/24374414/ https://pubmed.ncbi.nlm.nih.gov/27521368/ https://academic.oup.com/jamia/article-abstract/27/4/606/5782094)