July 15, 2021

Representative Diana DeGette  
US House of Representatives  
2111 Rayburn House Office Building  
Washington, DC 20515

Representative Fred Upton  
US House of Representatives  
2183 Rayburn House Office Building  
Washington, DC 20515

RE: 21st Century Cures 2.0

Submitted via email to Cures2@mail.house.gov

Dear Representatives DeGette and Upton:

Thank you for the opportunity to provide feedback on the 21st Century Cures 2.0 draft legislation. The past year the coronavirus pandemic has shown the increasing need for investing in our health system, and we applaud your continued leadership in this area.

Patient ID Now is a coalition of nearly 50 healthcare organizations representing a wide range of healthcare stakeholders, including patients, physicians, health information professionals, health IT companies, and public health, committed to advancing a nationwide strategy to address patient identification and matching.

Legislative Language Recommendation for Cures 2.0

The Patient ID Now coalition requests the following addition to the 21st Century Cures 2.0 legislation.

AMENDING THE SOCIAL SECURITY ACT TO REQUIRE THE DEVELOPMENT OF A STRATEGY FOR UNIQUE IDENTIFICATION OF PATIENTS

(a) It is the intention of the Congress to amend the Social Security Act in order to give the Secretary authority to adopt a national strategy for accurate patient identification and matching that may consist of one or multiple solutions, including but not limited to patient-empowered solutions, unique identifiers, demographic data standards, referential matching standards, or other solutions.

(b) Title XI of the Social Security Act (42 U.S.C. 1301 et seq.) is therefore amended by striking the word “individual” in Section 1173(b)(1) and inserting the following:

“(b): UNIQUE HEALTH IDENTIFIERS

(2) IN GENERAL—The Secretary shall adopt a national strategy providing for the accurate unique identification of each individual for use in the healthcare system.
In carrying out the preceding item, the Secretary shall take into account the goal of improving accurate identification and match rates, standardization, patient privacy and security, interoperability, data quality, patient access, and any other area the Secretary deems necessary.

(4) USE OF PATIENT IDENTIFICATION STRATEGY—The strategy or standards adopted under paragraph (2) for unique identification of individuals shall specify that the purpose for which the patient identification strategy may be used are limited to healthcare-related purposes.”

Need for a National Strategy on Patient Identification and Matching

For nearly two decades, innovation and industry progress have been stifled due to the narrow interpretation of a yearly appropriations restriction included in Section 510 of the Departments of Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) bill that prohibits the US Department of Health and Human Services from spending federal dollars to promulgate or adopt a unique health identifier for individuals. This archaic ban has had a detrimental impact across the healthcare system to patients, providers, and public health.

Failure to accurately identify and match patients to their health information raises serious quality of care and patient safety concerns. Difficulties in correctly matching patients to their health information across health information technology systems limits health information exchange, which can result in medical errors, delayed or lost diagnoses, duplicative testing, and wrong patient orders. The problem of patient misidentification is so dire that one of the nation’s leading patient safety organizations, the ECRI Institute, named patient misidentification among the top ten threats to patient safety. Patient matching issues can cause everything from delayed or unnecessary care, to adverse drug events, to even death.

The problem of patient misidentification extends to already overburdened hospitals and providers. Approximately 33 percent of all denied hospital claims are associated with inaccurate patient identification, costing the average hospital $1.5 million each year, and the healthcare system more than $6 billion. Patient misidentification costs the average clinician almost half an hour in wasted time per shift.

Now more than ever, the COVID-19 pandemic highlights the urgent need to implement a national strategy around patient identity. Accurate identification of patients is one of the most difficult operational issues during a public health emergency, including the gathering of patient demographic information (e.g.—address, phone, email, etc.) and ensuring such information remains attached to the correct patient. Temporary testing and vaccination sites in parks, convention centers, and parking lots have exacerbated these challenges.

---

1 Top 10 Patient Safety Concerns for Healthcare Organizations, Available at: https://www.ecri.org/EmailResources/PSRQ/Top10/2017_PSTop10_ExecutiveBrief.pdf
2 http://www.healthcarebusinesstech.com/patient-identification-errors/
3 https://www.securitymagazine.com/articles/88999-inaccurate-patient-ids-cost-hospitals-15m-a-year
The COVID-19 pandemic has also laid bare healthcare disparities in underserved communities and populations. According to OCHIN, a national, non-for-profit, health IT service provider for a national network of more than 500 healthcare delivery sites across the country—

- Black patients make up 13% of their patient population but **21% of duplicates**;
- Hispanic/ Latino patients make up 21% of the population that OCHIN’s members serve, yet they make up **35% of duplicates**;
- The homeless population makes up 4.3% of OCHIN patients, but 12% of its duplicates (**almost three times the expected rate**); and
- Migrant patients make up 2.1% of the OCHIN patient population but **3.6% of its duplicates**.

Because this ban was implemented before the full implementation and efficacy of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), the privacy considerations of today are much different than they were two decades ago. Without an actionable national strategy to address the ongoing and growing challenges of patient matching, patient care, safety and outcomes will be compromised.

Without a national strategy the healthcare ecosystem faces an “inverse” privacy problem – whereby individuals must repeatedly disclose individually identifiable information to each healthcare provider they see to accurately match the patients to their medical record. Furthermore, each payer still maintains separate proprietary identifiers for patients, increasing the number of identifiers in use. Even more worrying for patient privacy is risk of overlays—i.e.—the merging of multiple patients’ data into one medical record, causing patients to have access to other patients’ health information, which could result in an unauthorized disclosure under HIPAA. Patient identification strategies can begin to address these privacy concerns. For instance, Medicare established a new Medicare identifier after Congress mandated the removal of the Social Security number from claims pursuant to the bipartisan Medicare Access and CHIP Reauthorization Act of 2015, an effort aimed at enhancing patient privacy. Privacy is a top priority, but to do so, a national strategy to address patient identification and matching must be put into place.

The 21st Century Cures 2.0 Act aims to modernize several parts of our current healthcare system, including our public health systems and the Centers for Medicare and Medicaid Services (CMS). Yet as the US health system becomes increasingly interoperable, including between payers, plans, providers, and public health surveillance systems, patient misidentification is a continuing barrier to full interoperability and modernization. Now is the time to ensure that patient records are complete and accurate to facilitate increased patient safety, patient privacy, and public health efficacy.

Patient ID Now thanks Representative DeGette and Representative Upton for their leadership in modernizing and protecting our health system. We look forward to working with you to achieve these goals. Should you or your staff have any additional questions or comments, please contact Kate McFadyen, Director, Government Affairs, AHIMA at kate.mcfadyen@ahima.org or (202) 480-6058.

Sincerely,

Patient ID Now