

April 18, 2018

Public Comment in Opposition of the U.S. Department of Homeland Security (DHS) proposal to modify and reissue a current DHS Immigration and Customs Enforcement (ICE) system of records titled, “Department of Homeland Security (DHS)/U.S. Immigration and Customs Enforcement (ICE)-013 Alien Health Records System.” Docket number DHS-2017-0071

I. New York Lawyers for the Public Interest

For more than 40 years, New York Lawyers for the Public Interest (NYLPI) has been a leading civil rights and legal services advocate for New Yorkers marginalized by race, poverty, disability, and immigration status. Our work integrates the power of individual legal services, impact litigation, and comprehensive organizing and policy campaigns. Guided by the priorities of our communities, we strive to create equal access to health care, achieve equality of opportunity and self-determination for people with disabilities, ensure immigrant opportunity, strengthen local nonprofits, and secure environmental justice for low-income communities of color. In this time of great uncertainty and threat to our client communities, NYLPI fights to protect progress, build resilience, and pursue local innovation.

In the past five years alone, NYLPI advocates have represented thousands of individuals and won campaigns improving the lives of millions of New Yorkers. Our work with community partners has led to landmark victories including deinstitutionalization for people with mental

illness; access to medical care and government services for those with limited English proficiency; increased physical accessibility of New York City public hospitals for people with disabilities; cleanup of toxins in public schools; and equitable distribution of environmental burdens.

In addition, NYLPI's Pro Bono Clearinghouse provides critical services to strengthen nonprofits throughout every community in New York City. Drawing on volunteer lawyers from New York's most prestigious law firms, we help nonprofits and community groups thrive by providing free legal services that help organizations overcome legal obstacles, build capacity, and develop more effective programs. Through educational workshops, trainings for nonprofit leaders, individual counseling and a series of publications, the Clearinghouse is at the forefront of helping nonprofits maximize their impact on communities in each of your Districts.

NYLPI's Health Justice Program brings a racial justice and immigrant rights focus to health care advocacy in New York City and State. NYLPI has a long commitment to immigrant justice and the challenges faced by immigrant communities, with work ranging from individual representation to statewide advocacy campaigns focused on access to healthcare. Several years ago, NYLPI began a multi-pronged program to address access to healthcare in immigration detention. Through this program we represent individuals who are seeking better healthcare in detention, seeking release from detention, and attempting to access care in the community after release. We provide individual advocacy, litigation representation, and also connect individuals and immigration attorneys to medical providers through our medical-legal-community partnership. Through our work we have documented denials of vital treatment,

delayed surgeries, missed life-threatening diagnoses, and failure to provide discharge planning, while people are detained, as well as challenges accessing care after release. Much of our work over the last several years has been spent requesting and advocating for medical records for our clients, either while they are detained or after release and seeking care in the community. The later come as direct requests from medical providers seeking to provide care for those recently detained.

II. Access to medical information is a civil rights issue.

Access to medical information is a civil rights issue. When people with serious chronic medical conditions are released from immigration detention, they must be able to connect or reconnect with medical providers quickly to get the medical care that they need. Having access to a complete set of clear, unredacted medical records is a fundamental step in this process. This is because medical providers rely on medical records to piece together an accurate health history, and this translates to more effective and timely care. Access to medical records enhances doctor-patient communications because the flow of information helps reduce errors and improve the overall quality of care. The proposed rule constitutes a disruption of a well-established system of information sharing that will likely result in less access to medical information for previously detained individuals and their medical providers.

III. HIPAA fundamentally changed the health information landscape.

The implementation of HIPAA had the effect of altering the health information landscape. In the 15 years since HIPAA's inception, a system of sharing medical information among and between patients and their medical providers has emerged and taken root. Within

the medical field, it is generally understood and expected that HIPAA regulations control the way medical providers (hospitals/doctors) get access to patient medical records for the purpose of providing adequate care. The long established process generally involves faxing a HIPAA release, sometimes along with letter, to the provider. The records are then delivered to the requestor, within a reasonable time after the request. Changes to this process are likely to result in confusion, delays in the transfer of records which will likely translate to delays in receiving medical care for patients affected by this change.

IV. DHS's proposed change to a FOIA based medical records systems would likely disrupt customs established under HIPAA.

DHS's move to a FOIA-based medical records request system would likely be very disruptive to the existing HIPAA-based ecosystem. Medical providers, like most patients, currently have no need to interface with the FOIA process and therefore have little understanding of how it functions. Under FOIA, the potential negative effects of this disruption include: a worsening of doctor-patient communications, diminished flow of information, and an increase in errors and diminished overall quality of care for those affected. All of this combined, reinforces health disparities that are already prevalent among immigrant populations.

The HIPAA privacy rule established a patient's right to access their medical records. The promulgation of the HIPAA privacy rule reflects government's understanding of the key role that medical records play in aiding patients and caregivers to make informed health decisions. Under HIPAA medical records belong to the patient and must be delivered in their entirety

upon the patient's request. The current system relies heavily on the expectation that patients will have access to their entire, unredacted, medical file as is the current custom under HIPAA. This understanding would require a fundamental change with a switch to a FOIA-based process. Under FOIA, the medical records would likely be regarded as belonging to the government and would be subject to redactions based on the applicable exceptions in the FOIA statute, this change conflicts with the open approach to patient access of medical records under HIPAA. Diminished access to a complete and unredacted medical file is likely to have negative effects on patient care.

V. The proposed electronic patient record portal is not an adequate remedy to the disruption of the HIPAA and relies on faulty assumptions about the population affected.

DHS's proposed electronic patient record portal is *not* an adequate remedy for the disruption of the existing HIPAA-based system, because the new electronic system assumes that people will have access to a computer, a printer, and the internet, and that they will have a significant level of computer literacy. These assumptions are contrary to what is known about the access and use of technology among immigrant communities. It's well established that computer literacy, access to technology, and use of technology is significantly lower among immigrant communities in the United States than among the native-born population. Outside of the United States, internet access among the general population can vary widely by country and region. Given these known barriers to the communities most likely to need to interface with proposed system, it follows that this system cannot be considered an adequate remedy.

In this way, DHS's proposed system will be one more in a vast field of disjointed and proprietary Electronic Medical Records systems (EMRs); each of which is owned, operated, and controlled independently, and which generally lacks the ability to communicate with the others. For patients and medical providers, this means that despite existence of an EMR, it is unlikely ICE will be able to electronically transfer medical records from their system to that of the patient's medical provider (assuming the medical provider even has access to an EMR).

VI. Conclusion

The proposed changes are likely to be very disruptive to the existing landscape of access to medical records that emerged with HIPAA. The proposed systems do not provide meaningful access to medical records for the affected communities, which already face barriers to accessing healthcare. The net results of the proposed rule and new barriers it would create, are likely to include negative health outcomes and increases health disparities for immigrant communities. For these reasons, we oppose the proposed change to a FOIA-based system and any suggestion that the proposed EMR system would alleviate any hardship that would arise from the FOIA-based system.