



January 28, 2019

Dr. Don Rucker, MD
National Coordinator for Health Information Technology
Department of Health and Human Services
200 Independence Avenue, SW
Washington, D.C. 20201

Re: Strategy on Reducing Regulatory and Administrative Burden Relating to the Use of Health IT and Electronic Health Records (EHRs)

Dear Dr. Rucker,

The National Partnership for Women & Families appreciates this opportunity to comment on the Strategy on Reducing Regulatory and Administrative Burden Relating to the Use of Health IT and EHRs. As a leading non-profit, consumer advocacy organization working to promote access to high-quality health care, we share the Administration's vision of a health IT ecosystem that supports providers and individuals to achieve the best possible care for the patient. Women stand to benefit greatly as our nation's care-coordinators-in-chief: women make about 80 percent of health care decisions and provide nearly two-thirds of family caregiving in our nation. Efficient, convenient access to online health information can help women make informed decisions about their care and that of their loved ones.

Unfortunately, the current design and implementation of health IT products, including EHRs, frequently makes online information sharing more difficult for providers, patients and their caregivers. We recognize that the 21st Century Cures Act instructed HHS to identify ways to reduce regulatory and administrative burdens relating to EHR use. The design and usability challenges with EHRs have been well-documented for providers; less well so for patients. Given that patients and family caregivers are [the fastest growing user group](#) for electronic health records (EHRs)¹ and are directly affected by their providers' use of these and other digital health technologies, we urge the Administration to produce a companion report that examines EHR-related burdens affecting care delivery from the consumer perspective.

For example, the patient portals tethered to most EHRs have yet to reach their potential for secure information sharing and patient engagement. Portals seem ubiquitous but not robustly used: recent data indicate that while 52 percent of Americans were offered access to an online health record by a provider or insurer, just over half (53%) of those actually viewed their record at least once within the past year. [Our work with patients and providers](#) to improve information sharing has illuminated several challenges of patient portals that generally fall into three categories: 1) availability of information; 2) usefulness of information; 3) usability of the portal.

Many patient portals are difficult to access the first time, and/or contain missing, out-of-date, or simply unhelpful information: patients and caregivers have described the after visit summaries as “meaningless.” Individuals often express frustration that they cannot find the information they are looking for – whether it’s health history that predates the EHR, data stored in a different system, or information that’s not routinely made available on the portal (e.g., sensitive test results). Even when data is available, patients may not know how to interpret or act upon it. Patients struggle to understand medical jargon and clinical terminology used in discharge summaries or lab results. Making clinical progress notes available on the portal (e.g., OpenNotes) continues to be the exception rather than the rule, even though notes are enthusiastically embraced by individuals and often provide missing context and insight.

Additionally, some providers choose not to turn on the secure email messaging or note sharing features of their portals - functionality that would enhance the value of portals and more meaningfully engage patients. Patients find supplementary “convenience” features of many patient portals such as online scheduling and medication refill requests to be very beneficial, but are discouraged when these functions are not available or unreliable.

When people need more information – a detailed health history for a second opinion or to switch providers, for example – they typically make a medical records request, a process that remains stuck in paper copies and fax transmissions. Patients are not offered their data in structured formats that can be uploaded into health apps, and providers are often unaware of their own EHR’s capabilities to extract and share data in these more usable formats. Unreasonable fees for medical records or other health data continue to pose a significant barrier to patient access.

We urge the Administration to explore these and other barriers related to the use of health IT that are adversely affecting peoples’ ability to manage their health or coordinate their family’s care. In addition to documenting EHR-related burdens from the patient perspective, we encourage the Administration to articulate how it will evaluate existing and future measures that may impose some level of burden on providers against the benefit those measures may provide to patients and family caregivers. For example, the report notes provider concerns about measures requiring direct patient action – such as view/download/transmit or secure messaging – as particularly burdensome. *Yet these are exactly the measures that hold the most promise/potential for patients and families.* Recent data show that provider involvement yields significant benefits in patient uptake of patient portals: individuals encouraged by their health care provider to use their online medical record were nearly two times more likely to use their online medical record compared to those who were not encouraged to do so.² We must find the right balance of reducing provider burden and improving patient experience, engagement and convenience. As Atul Gawande notes in his recent article on why doctors dislike their EHRs: “If computerization causes doctors some annoyance but improves patient convenience and saves lives, isn’t it time we all got on board?”

Thank you once again for this opportunity to provide input. We are eager to work with the Administration to reduce barriers to effective use of health IT and improve the experience and functionality of online access for patients and families. If you have any questions about

these recommendations, please contact me at (202) 986-2600 or
kmartin@nationalpartnership.org.

Sincerely,

A handwritten signature in black ink that reads "Katie Martin". The signature is written in a cursive, flowing style.

Katie Martin
Vice President, Health Policy and Programs

1 <https://www.newyorker.com/magazine/2018/11/12/why-doctors-hate-their-computers>

2 Patel V & Johnson C. (February 2018). Consumers' use of online medical records and devices for health needs. ONC Data Brief, no.40. Office of the National Coordinator for Health Information Technology: Washington DC.