

The Download Capability

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POLICY BRIEF

“As the Markle Foundation puts it, the technology must be designed in such a way that ‘decisions about linking and sharing are made at the edges of the network’ by patients in consultation with their doctors, and never inside the network. This goes to the very heart of the matter. For even though it is fine to start hoping for the day when interoperable electronic health records create vast pools of medical information that could be used to find new cures and battle epidemics in real time, their ultimate purpose is to make one simple and shockingly overdue change: to enable individuals, at last, to have access to, and possession of, information about their own health.”

—THE ECONOMIST, April 2005

Health Information

...at the click of a blue button

As billions of dollars of federal funding begin to flow into health information technology (health IT), we ask a simple question: *Shouldn't there be a simple way for individuals to get electronic copies of their own health information?*

Now more than ever, policy makers and health leaders are betting on health IT to address the nation's pressing need to improve health through higher-quality, more cost-effective care.

To be successful, this effort must engage patients and their families. Information is a foundational requirement for individuals to become active participants in achieving health-improvement and efficiency goals targeted by health IT subsidies under the American Recovery and Reinvestment Act of 2009.

In light of this opportunity, Markle Connecting for Health, a public-private collaborative, envisions a common signal to consumers such as a “blue button.” People would come to expect that they could log in and click the blue button to download their own health information from secure Web sites offered by medical practices, hospitals, insurers, pharmacies, and laboratory services.

Why a blue button?

Several surveys show Americans overwhelmingly believe that using an online personal health record (PHR) that includes electronic copies of health information would provide major benefits. At least 86 percent of respondents say that PHRs could help them avoid duplicated tests, keep doctors informed, move more easily from doctor to doctor, check the accuracy of their medical records, and track personal health expenses.¹

The Recovery Act clearly sets the expectation that individuals will be able to get electronic copies of pertinent health information about themselves. Compared to more sophisticated health IT functions, a blue button is a relatively low-cost and low-burden means for health care providers to comply with the law. Yet today, this simple capability is rarely offered.

If it became a common feature of health IT, the blue button would:

- Change consumer expectations and help them become more efficient in managing their health information.
- Increase market pressure for technical standards to exchange electronic health data.
- Enable innovation through a host of applications and services that could add significant value to individuals by using their information with their permission, such as tools to help people with diabetes track their blood sugar, medication use, and preventive care.

How should privacy and security be protected?

As with any health IT feature or service, the download capability must be implemented with attention to sound privacy.

Markle Connecting for Health has developed a set of privacy and security practices to guide implementers. This new policy guidance builds on the Markle Connecting for Health Common Framework for Networked Personal Health Information²—a set of policies and practices that, when taken together, provide a foundation for all health IT tools directed at consumers.

Services that offer the download capability to individuals, and services that seek to make use of the downloaded information on the individual's behalf, should abide by the full complement of policies and practices in the Common Framework.

1 [*Americans Overwhelmingly Believe Electronic Personal Health Records Could Improve Their Health*](#), Markle Foundation survey conducted by Knowledge Networks, June 25, 2008. Available online at www.markle.org/publications/401-americans-overwhelmingly-believe-electronic-personal-health-records-could-improve-t.

2 [*The Markle Common Framework for Networked Personal Health Information*](#), developed and endorsed by 56 diverse organizations, details policies and practices to enhance individual access to personal health information and protect privacy. Available online at www.markle.org/health/ccf.

Specific to the download capability, our key recommended practices are as follows.

Help individuals make informed choices.

Any organization offering the download button should **inform** individuals about the choice to download information and **confirm** that the individual wants to do it. When an individual is downloading information to a computer or a device, the provider of the download capability should abide by the following guidelines:

- Provide a clear, concise explanation of the download function and its most fundamental implications for the individual.
- Provide prominent links that enable individuals to view more details about the download process, including what basic security precautions to take on their own, how the service answers questions, and who to contact if they believe some of the downloaded information is in error.
- Obtain independent confirmation that the individual wants to download a copy of personal health information after presenting, at minimum, the following information:

Health records can contain sensitive information.

If you download sensitive information to a shared or unsecured computer or device, others might see it.

You are responsible for protecting the information you download, and for deciding with whom to share it.

Are you sure you want to download a copy of your personal health information to the computer or device you are using?

Yes No Tell Me More

Make it available to the right person (and the right machines).

Given that patient engagement is a federal health IT priority, there is a need for federal guidance on acceptable thresholds for identity proofing and authentication of individuals.

As the download capability becomes a common feature on patient portals and other personal health information services, structured health data becomes more easily harvestable by automated processes, whether acting as legitimate proxies or as impostors. We recommend the following protections:

- Deploy separate pathways for download requests from the individual, and download requests via automated processes acting on the individual's behalf.
- On human-accessible download pages, deploy an effective means to determine whether a real person is requesting the download.
- Keep a record of download events in immutable audit logs.
- Consider enabling individuals to set up automated notifications for each time their information is downloaded.
- Include source and time stamps for data entries in the information downloads.

“For the first time ever, veterans will be able to go to the VA website, click a simple blue button and download or print your personal health records so you have them when you need them, and can share them with your doctors outside of the VA.”

—President Barack Obama

Call to Action: Make the Blue Button a Priority

We encourage the US Department of Health and Human Services to make the Blue Button a priority in all health IT efforts.

- Specify the download capability as an allowable means for providers to deliver electronic copies of health information to individual patients consistent with the policy and technology recommendations of the Markle Connecting for Health Common Framework.
- Make the download capability and our policy recommendations a requirement of qualified health IT so that providers using qualified systems will have this capability.
- Make the download capability a core requirement for federal- and state-sponsored health IT grants and projects.

We encourage private sector organizations that are custodians of personal health information, as well as health information exchanges (HIEs), to do the following:

- Include the download capability in procurement requirements along with the privacy practices we recommend in with the full Markle Connecting for Health Common Framework.
- Implement the download capability consistent with the policy and technology recommendations of the Markle Connecting for Health Common Framework.

The Time Is Now

As evidenced by the President’s announcement to offer the blue button to veterans, and similar plans for MyMedicare.gov to offer it to Medicare beneficiaries, many organizations are working to make the blue button a reality. If implemented with sound privacy practices, this little blue button can make a big difference. ■

For the full set of recommendations by the Markle Work Group on Consumer Engagement and the list of 49 supporting organizations, please see *Policies in Practice 1: The Download Capability* available at www.markle.org.