

# Electronic Health Records and Your Privacy



## WHAT YOU NEED TO KNOW ABOUT ELECTRONIC HEALTH INFORMATION

### What are electronic health records and health information exchanges? How will they affect me?

Our nation's health care system is in a period of rapid and dramatic change—the way that our health information is stored and shared is a big part of that transformation. Many health-care providers are already using electronic health records to store patients' medical information. If your doctor isn't doing it now, she will. States and the federal government are developing electronic networks that will allow that information to be shared by all health care providers.

In New York State, networks run by regional health information organizations (RHIOs) are already allowing health care providers to share patient information among participating providers within those regions. Eventually, these networks will be linked by the New York State Health Information Network. At the same time, the federal government is developing networks that will allow records to be shared across the nation.

### Sharing health information provides real benefits to patients:

- Improved care through greater coordination of health care services
- Test results available across the network may require less testing, speeding care and lowering cost
- Fewer medical errors, misdiagnoses and conflicting medications

### But health information exchange in New York State does raise some concerns:

Despite the benefits to patients, easily shareable electronic records can lead to threats to patient privacy, including the potential for security breach, misuse of information and loss of patient control over confidential and sensitive health information. Given these risks, it should be the patient who chooses whether or not to participate.

- **Patients have a right to know.** New York State should conduct public outreach and education about health information exchange that is more than simply an ad campaign to encourage everyone to sign up. Patients must understand the risks and benefits of participating before they get to their doctor's office.
- **Any participation must be based on consent.** Right now, there is no requirement that patients consent before their health care provider links their medical record to a broader electronic network. Patients should be given a choice about whether they want their medical information to be linked to a network that allows for easy sharing *before* it happens.
- **Patients should be told their records are available in emergency situations.** Patients have to give their providers permission to access their electronic health information, except in emergencies where state policy allows providers to “break the glass” if patients have not given consent. Consent forms should allow patients to choose between emergency-only access, a range of routine access options, or no access under any circumstances.

- **Even simple identifying information can be sensitive.** Access to patient names or addresses may pose a threat to patients at risk of domestic violence, minors, and other vulnerable groups. Patient consent should be required before identifying information is included in the system or patients should be allowed to require protection for such information.
- **Every provider doesn't need a patient's entire medical history.** In New York State, giving a provider permission to download a patient's medical information means that the provider sees the patient's entire medical record, including sensitive information such as substance abuse treatment, mental health conditions, abortion and other reproductive health. Patients should be able to shield such information or decide to share it with only some providers. Otherwise, the patients who most need help may refuse to participate for fear of discrimination, breach of confidentiality, or mistreatment. Patients should be able to choose which data is shared with which providers.
- **Young people have unique concerns about medical information privacy.** In New York State, minors can consent to specific types of health care, including reproductive health and certain mental health treatment. Parents and providers may not get information about this treatment without the minor's permission. In New York State's "all-or-nothing" system, minors between the ages of 10 and 18 are excluded because there is no way to guarantee their privacy. Minors must be able to get the benefit of participating in health information exchanges while maintaining control over their sensitive health information.
- **Patients must control their data, in and out of the health care setting.** Patients must be allowed to correct information that is wrong in their files and networks must be responsible for making sure those corrections are made throughout the system. The state must make sure that patients are protected against security breaches, but also against misuse of information by health-care providers and staff employed by providers, business associates and others who have access to their files. Additional care is needed when individual health information is used for research or public health purposes.

**The current "all or nothing" system for sharing health information will wind up excluding many people. Consider these scenarios:**

- ***Minors Left Out.*** *Evan is a sexually active 15 year old being treated for gonorrhea. He wants his other doctors to know about that, but not his parents. This is impossible under the current system, which excludes information about minors between 10 and 18.*
- ***Dangers of Identifying Information.*** *Denise and her children have fled an abusive partner who has access to medical records either as a health care provider or a service provider to a health care information network. She's afraid to seek medical care for herself and her children because her personal information, including her address, will be included in an electronic network that may be easily accessible to her partner.*
- ***Sensitive Information from the Past.*** *Jane was sexually assaulted in her 20s and briefly took antidepressants to deal with the trauma. She has put this behind her, but is afraid to consent to participate in her doctor's RHIO because she doesn't want all of her doctors to know about the rape and depression she suffered.*