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Health Information Security and Privacy Collaboration

Guide to the Self-directed Consumer Tutorial on Privacy, Security, and Sensitive Health Information

Prepared for

RTI International

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Consumer Education and Engagement Collaborative

Massachusetts

Health Information Security & Privacy

COLLABORATION



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1. BACKGROUND AND DESCRIPTION OF PROJECT

Patient health information held by doctors, hospitals, other health care providers, and insurance companies is required to be protected under both federal and state law. In Massachusetts, health information can generally be shared for treatment and payment purposes (e.g., with other health care providers for consultation purposes or for billing purposes). There are a few exceptions, however, when patient health information may not be disclosed without the express consent of the patient. In those cases, such consent must be in writing. This requirement is due to the Massachusetts privacy statute, laws governing health care providers and insurers, and case law resulting from court decisions.

Certain kinds of “sensitive” health information, including behavioral health information, genetic test results, and HIV test results, are subject to additional legal protections in Massachusetts. This may include a requirement that express written consent be obtained for each release of sensitive health information. Other requirements may relate to the form of the consent, or additional information that must be provided to the patient at the time of consent.

In very limited circumstances, disclosures of sensitive health information are still permitted without patient consent. For example, health information revealed to psychologists, psychotherapists, or social workers during the course of their examinations may be disclosed to others in certain situations (when necessary to prevent serious harm to the patient or others). Additionally, health care providers are often allowed to release a patient’s sensitive health information in the event of an emergency, when obtaining a patient’s consent is not practical.

Communications made by a patient to a behavioral health care provider, such as a social worker, psychologist, or psychotherapist, are also privileged, which means that they cannot be disclosed in a court proceeding without the consent of the patient. Exceptions exist, however, to allow disclosures in certain situations where the patient’s emotional status has been raised or brought into question, or in cases in which a judge rules that the need for the sensitive health information in a legal proceeding outweighs the privacy rights of the patient.

This Massachusetts tutorial development project is part of a multimodal approach to educating and engaging consumers regarding the privacy and security of sensitive health information and its sharing requirements. It presents definitions with examples, patient rights and exceptions, suggested questions to ask providers, and embedded self-tests for the information presented.

The tutorial was created in a Microsoft PowerPoint format for ease of storage, transfer, and display. In addition, this format allows easy customization for diverse Massachusetts

organizations as well as other states. A guiding principle for development was that consumers did not need to complete the entire tutorial but rather could choose those sections of immediate need or interest.

1.1 Process

The attached tutorial was developed by initially creating a “storyboard” and logic flow so that certain types of information could be grouped into modules (e.g., mental health or HIV/AIDS). Templates for each kind of sensitive health information were developed to include: definitions, patient rights, exceptions under Massachusetts law, frequently asked questions (FAQs), suggested questions to ask providers, and a “self-test” section. Next, the content was created, in part, using information from the other Massachusetts consumer education and engagement (CEE) projects. The content modules were linked together and offered in a straightforward academic format. Drafts were then distributed for review by the Health Information Security and Privacy Collaboration (HISPC) Multistate CEE Collaborative, the Massachusetts HISPC workgroup, and the Massachusetts HISPC steering committee. In order to ensure accessibility for a wide target audience, a literacy review was performed and revisions were completed based on those recommendations.