Picture This: Illustrating the Future of HIPAA Documents

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A single visit to a new health care provider can leave patients with a pile of paperwork. There are consent forms, appointment reminders, prescriptions, and various other instructions that they are expected to review and comprehend in short order. In that pile, one of the documents that is most tempting to skim rather than read is the “Notice of Privacy Practices,” due to its length, complexity, and the fact that patients only have to acknowledge receipt of the form, rather than agreement with it.

The Notice of Privacy Practices is a portion of the information governed by the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule. HIPAA was enacted by the United States Congress in 1996, in part to establish a framework for protecting the privacy, security, and availability of patient medical information. The Rule requires covered entities to give patients notice of their institutional privacy practices. This notice must explain how the entity can use and disclose the individual’s protected health information, and the patient’s rights in relation to those uses. The Rule divides uses and disclosures of personal health information into two general categories: those that require patient authorization and those that do not (there are also a few special circumstances where patient consent is not required, but objections are honored). Covered entities must obtain written consent from patients in order to use patient information requiring authorization, but only need to provide documentation containing “sufficient detail to place the individual on notice of the uses and disclosures that are permitted or required” for the rest.

Preliminary studies suggest that patients are not coming away from HIPAA forms with a clear understanding of what uses and disclosures it covers. This violates the spirit, if not the letter, of the law. If notice is important, then it stands to reason that comprehension is as well; otherwise, the HIPAA notices given to patients are mere formalities. What can be done to improve patient understanding of HIPAA documents? Using plain language is crucial, but the information remains challenging to comprehend even when written at an eighth-grade level, since it contains many discrete details that do not follow a narrative flow. Moreover, the information itself is dry; it is questionable whether patients would be interested in reading it even if it were presented in completely clear prose. A new approach is required. In recent years, there has been a rise in the use of stylized, comic-style illustrations for patient education purposes. Graphic documents convey complex information in an engaging, accessible format. Could a similar approach aid patient understanding of required HIPAA documentation?

Two illustrated HIPAA documents have been developed at our institution; the required Notice of Privacy Practices, and an authorization to use and disclose personal health information for...
research purposes. They are based on the Institutional Review Board (IRB)-
approved written documents currently in use at Mayo Clinic, but contain far less
text. Our commitment to producing an illustrated form meant that it was necessary to control the amount of text we included, lest the new form become nothing more than a typical written form accompanied by illustrations. It is important to emphasize that while text was omitted, pertinent information was not. Where traditional HIPAA forms would have included extensive lists of possible disclosures, we distilled the information into short written explanations that could be further “explained” through accompanying illustrations. For example, the Mayo Clinic Notice of Privacy Practices contains an eighty-word statement detailing the possible use of patient information to contact individuals in order to request philanthropic contributions to the institution. The graphic form conveys this idea with a drawing of an envelope and the word “donation.” The same information is conveyed, but in a much more concise manner.

The illustrated Notice of Privacy Practices form starts from the point of view of an imagined recipient. This character’s questions and concerns are used as a device to gain readers’ interest and emphasize why they should care to understand the information at all. It shows the imagined recipient of the form sighing in resignation as he attempts to understand the form and empathizes with his temptation to simply sign it rather than spend the time deciphering it. A helpful representative of the health clinic shows up and informs him that his health information might be shared with a few other people as well. Rather than use language that downplays concerns that a reader might have about this statement, the illustrated form takes full advantage of these, showing the main character unhappily concerned about what this could mean in order to hook readers in and make them want to learn more.

While the Notice of Privacy Practices form begins and ends with a conversational style, it switches to a more didactic tone in the information-heavy middle sections of the notice. This enables a large amount of information to be conveyed in a concise way. Creating a narrative series for each potential use of protected health information could have resulted in a book-length work, which, while interesting, would not be something that could be reviewed prior to a reader's office visit. The illustrated elements are used to organize the information, indicate levels of information, and to provide vignettes to further clarify what the statements mean. There is a hierarchy both to the page itself and within each frame. The title of each frame provides a headline for the intended use of the information—e.g. “for quality of care”—while the copy and pictures within the frame provide more detail about that usage. The illustrations also suggest example scenarios for the reader. The “if you are in the hospital” illustration brings to mind a scene where a concerned family member is looking for his or her loved one. Patients can easily relate to the need for such a disclosure, in contrast to the confusing terminology used to convey the same information on the traditional form which refers to sharing information for “Facility Directory/Patient Census.”

The choices about the style of drawings used on the illustrated forms were made as deliberately as those pertaining to the content and layout of the document. These example forms use a very simplistic, cartoonish style with minimal detail. Despite the straightforward line style, different combinations of eye, eyebrow, and mouth shapes can still be used to convey emotions like thoughtfulness, confusion, and satisfaction. The simplicity of the illustrations

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works to balance the visualdenseness of the text. Hand-written text, rather than a standard type font, was also a purposeful choice for this example, meant to avoid a dissonance between the organic style of the drawing and the potential rigidity of a traditional font.

The illustrated HIPAA documents contain general rather than state-specific information, and are intended to serve as prototypes of what graphic HIPAA forms could look like. The presence of this tangible example advances the concept of nontraditional HIPAA documents in more meaningful ways than an abstract discussion could. It not only gives those who could not imagine an illustrated form a chance to see a concrete example, but it also shows that conveying complicated information in a non-traditional format is indeed possible.

Our goal in developing illustrated HIPAA forms was to create something that is not only understandable, but also interesting to read. Infusing the dull information on these documents with interesting, yet concise, narrative details proved challenging, but doable. The illustrated forms displayed here are just one example of how this challenge can be approached. At this point, it is too early in the process to conduct quantitative evaluations of the graphic format. It is important to give a novel approach like this a chance for further development. A common response to something unfamiliar is often disapproval, regardless of its potential. Allowing critics a chance to become accustomed to the novel format before inviting feedback will increase the likelihood that they will fairly judge the concept for its potential to improve patient interest and understanding. The forms were not developed to show the sole way that illustrations can be used in conveying HIPAA information, but rather to begin a conversation at Mayo Clinic about the use of illustrations on medical and legal documents.

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1 45 CFR §164.520(b)(ii) (2010).
2 §164.520(b)(6).