

How De-Identification Has Turned HIPAA on its Ear

(And Other HIPAA Tidbits Pertinent to Those of Us in Private Practice)

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Is It Possible to Be Exempt from HIPAA in 2024?

As soon as I answer “No” to that question, someone would write me, explain their situation, and I’d find myself in the position of needing to write a retraction. So let me just say that at this point in time, I’d be hard-pressed to come up with a scenario of how one might pull that off.

In the past, YES. When HIPAA was enacted in 1996, some psychologists and other healthcare providers opted to abstain from actions that would trigger HIPAA. They kept only paper-pencil records, refraining entirely from creating or storing digital files on any device. They never submitted insurance claims electronically. By taking these precautions, they did not consider themselves to be Covered Entities (CEs).

However, when COVID began, many who had never used electronic tools, felt that taking the digital plunge had become necessary. They started with video software but may soon have found themselves needing other tools for routine tasks. Although some discretion was allowed in the early stages of the pandemic (Office for Civil Rights [OCR], 2020), providers were encouraged to get HIPAA Compliant products that provided Business Associate Agreements (BAAs), as soon as possible. At the time, getting a BAA was considered “best practices”. However, this is the issue:

BAAs – which are legally binding contracts, but ONLY for Covered Entities – almost always start with a statement similar to this:

“This document is an agreement between X, a software company and Y, a Covered Entity.”

If you’ve signed a document like that that attests to the fact that you ARE a Covered Entity, you might have a hard time convincing an auditor or a court that you are not. It only takes one such signed document to flip the switch. Once HIPAA is triggered, it’s triggered – it can’t be undone. There ARE some exceptions when HIPAA Does NOT Apply, such as when the information doesn’t constitute PHI, when it’s used for specific research or public health activities, or when it’s handled by certain entities like schools, employers, or law enforcement. But unless you fall into one of these categories, it’s likely safest to assume that you’re a Covered Entity.

There’s also a somewhat nasty double-bind here:

- If you claim you’re NOT a Covered Entity, your BAA is null and void since BAAs only apply to CEs.
- However, if you ARE a Covered Entity, you’re required to comply with HIPAA.

Not long ago, at this juncture, I would have pointed out that becoming compliant with HIPAA didn’t have to be a heinous or expensive task. Whether you would want a BAA was almost a no-brainer, since they were intended to provide additional peace of mind for both providers and their patients. My suggestion would have been to just bite the proverbial bullet, become compliant with HIPAA, and continue using HIPAA Compliant Software that provided BAAs. However, recently, some healthcare software companies have reworded their BAAs in ways that are contrary to how Business Associate Agreements were originally intended to be used. Here’s the story:

BAAs: What They Were Intended to Be and What They've Become

The concept of a “Business Associate” (BA) was introduced in HIPAA’s Privacy Rule as “a person or entity that performs certain functions or activities that involve the use or disclosure of protected health information on behalf of, or provides services to, a covered entity” (OCR HIPAA Privacy, 2002, 2003). The definition was expanded in 2009 by the Health Information Technology for Economic and Clinical Health Act (HITECH), requiring BAs to comply with many of the same privacy and security requirements that apply to Covered Entities. The HITECH Act also required Business Associates to provide CEs with Business Associate Agreements. Finally, the Omnibus Rule of 2013 extended a BA’s responsibility to safeguard a CE’s Protected Health Information (PHI) such that if there was a breach caused by the BA’s company or product, the BA was at fault, not the CE. BAAs were also required to specify how they used and intended to use the PHI that had been entrusted to them.

The intent of these laws was to encourage software developers to build secure healthcare products. The logic was that if a company knew they would be held accountable, they would offer safer products and services. It was hoped that the requirement of transparency would encourage ethical business practices. The original purpose of a BAA, then, was to provide a layer of protection for Covered Entities and their patients.

Recently, however, certain healthcare apps, including at least one EHR, had to revise their Terms of Service because of updated privacy regulations required by certain states. To meet the new requirements, these companies altered their Terms of Service and BAAs. Although the changes they made were legally compliant, the companies no longer offered the same level of assurance for Covered Entities (CEs). In fact, the new Terms did just the opposite. The key to how they managed to do this has to do with de-identified data.

De-identification

De-identification of PHI, by itself, is neither good nor bad. The issues are more about how it’s done, whether it’s done correctly, and the purpose for the de-identification. We’ll look at each separately.

How De-identification is Done

HIPAA is quite clear about how to de-identify data. There are two methods that can be used. The one used most often, which also produces the best results, is called the Safe Harbor Method. According to the provisions outlined in HIPAA’s §164.514(b), the Safe Harbor method for de-identification lists the following 18 identifiers of the individual or of relatives, employers, or household members which must be removed:

- A. Names
- B. All geographic subdivisions smaller than a state, including street address, city, county, precinct, ZIP code, and their equivalent geocodes, except for the initial three digits of the ZIP code if, according to the current publicly available data from the Bureau of the Census:

1. The geographic unit formed by combining all ZIP codes with the same three initial digits contains more than 20,000 people; and
 2. The initial three digits of a ZIP code for all such geographic units containing 20,000 or fewer people is changed to 000
- C. All elements of dates (except year) for dates that are directly related to an individual, including birth date, admission date, discharge date, death date, and all ages over 89 and all elements of dates (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older
- D. Telephone numbers
- E. Vehicle identifiers and serial numbers, including license plate numbers
- F. Fax numbers
- G. Device identifiers and serial numbers
- H. Email addresses
- I. Web Universal Resource Locators (URLs)
- J. Social security numbers
- K. Internet Protocol (IP) addresses
- L. Medical record numbers
- M. Biometric identifiers, including finger and voice prints
- N. Health plan beneficiary numbers
- O. Full-face photographs and any comparable images
- P. Account numbers
- Q. Any other unique identifying number, characteristic, or code, except as permitted by paragraph (C) of this section; and
- R. Certificate/license numbers

That SOUNDS like it should be straightforward, but it's not. One issue is that medical records are a combination of structured and unstructured data (also called "free text"). De-identification software and anonymization platforms used to scrub medical records and remove identifiers are reasonably good at detecting and removing PHI from structured data. However, PHI in free text sections are not always clearly labeled (Dorr et al., 2006; Uzuner et al., 2007). This might mean, for example, that the clinical notes we enter into our Electronic Health Records or other note-taking software could be treasure-

troves of identifying information, even when we're reasonably careful with how we write them. This is because, except for structured questions in the notes, what we write would be in free text areas of the application. Another place de-identification software could easily miss identifying information would be on files or forms a therapist might upload into their file storage application or that portion of their EHR. Those kinds of documents – typically PDFs or Word documents – often contain all sorts of information, including assessment results, that could be harmful to our patient if it were to get out.

Whether De-identification is Done Correctly

The topic above reveals problems that occur when de-identification is done correctly. However, we may be taking too much for granted when we assume companies are doing it right. For example, some companies claim to use initials to identify patients, citing that as evidence that they're de-identifying PHI (Dalton, 2023). However, according to HIPAA, initials are considered PHI when those initials are maintained in a designated record set (U.S. Department of Health & Human Services, n.d.). It is unclear whether the companies doing this are unaware of correct de-identification practices, or whether they are choosing to ignore them. Either way, each potential identifier that is NOT removed increases the possibility of recognition.

De-identified data is not considered foolproof. Even when it is done properly, individuals can sometimes be recognized from re-identified data (Benitez, 2010; Sweeney, 2000). However, even though de-identification doesn't ensure complete protection or confidentiality, it IS legal and – most importantly for our discussion – de-identified data is no longer considered PHI.

The Purpose for De-identifying the Data

This final discussion point – the purpose for de-identifying data – is what has thrown HIPAA on its ear. In other words, the issue is not that companies are de-identifying data, it's the rights they are assigning themselves by doing it. Companies are claiming that they de-identify all PHI they receive from their subscribers. De-identified data is not considered PHI. The companies argue that because they de-identify all data, the following are true:

- All data entered into their program belongs to them (since they de-identified it, it is now their data, not your PHI).
- As a result, they can do anything they want with it – sell it to any buyer they can find, use it to train AI models, etc. Furthermore, they refuse to disclose how they use this data. It's their data to do with as they please. They are not required to disclose their internal business practices to their customers.
- This may also mean that they are no longer on the hook for breaches. Breaches apply to PHI, but de-identified data is no longer considered PHI. Any mishaps that occur with de-identified data fall into the "unfortunate accident" category. Your clients may have been part of the unfortunate accident – possibly even identified from it – but it's not a breach. Because it's not a breach, there's nothing the company must do to remedy the situation or try to prevent it from happening again. But what if there IS some kind of incident where patients are identified. Are those considered breaches? If so, are you on the hook for those breaches? Or what if you enter data into the program in the afternoon, the company does routine de-identification sweeps

every night at midnight, but there's a breach during the window before the data was de-identified? Who's responsible for that?

Clearly BAAs like this, originally intended to help us, no longer do so. Some therapists have mistakenly concluded that since these companies are still claiming to be HIPAA compliant, they do not need to worry about the new Terms. This is wrong for several reasons.

HIPAA Compliant Software?

First, technically speaking, there is no such thing as HIPAA compliant software. Software cannot be a Covered Entity, and only CEs can be HIPAA compliant. Using “HIPAA compliant software,” means that, assuming you use it correctly and are complying with all other HIPAA requirements, YOU can be in compliance with HIPAA.

Second, although the Office of Civil Rights (OCR) indicates that healthcare software should be encrypted, it doesn't specify the type of encryption that must be used. This was a wise move for two reasons:

- Technology is constantly changing. Specifying cutting-edge encryption available when HIPAA was enacted on August 21, 1996, would have quickly become outdated.
- The authors of HIPAA were not experts in technology. By not specifying the type of encryption, they were leaving those kinds of decisions up to the experts in the field, which is as it should be.

However, the fact that the type of encryption is not specified has also allowed software developers a great deal of latitude. Some companies, for example, knowingly use encryption that is only secure 80 - 85% of the time (Google Transparency Report Help Center, n.d.). This is legal. Although a bit on the absurd side, technically, if a product is only encrypted 10% of the time, the BA has still fulfilled their HIPAA obligation. When we put this fact together with data that may be incompletely or inaccurately de-identified, the likelihood that our client's data may not be adequately protected is very much in question.

Ethical Considerations

So yes. These companies are operating legally. But are they ethical? Can you use these products and still maintain the ethical standards of your profession? All healthcare professions have ethical codes concerning confidentiality. APA's Section 4: Privacy and Confidentiality, includes two standards that are especially pertinent here: 4.01 Maintaining Confidentiality and 4.02 Discussing the Limits of Confidentiality. These two standards specify that psychologists “have a primary obligation and take reasonable precautions to protect confidential information obtained through or stored in any medium.” Furthermore, psychologists are to discuss with their patients “(1) the relevant limits of confidentiality and (2) the foreseeable uses of the information generated through their psychological activities (American Psychological Association, 2017).”

In a blog post titled “It had to be you: When your favorite EHR makes you break up with them,” Dr. Keely Kolmes provides compelling evidence that using such products may well put us in violation of our ethical guidelines (Kolmes, 2023). In addition to confidentiality issues, Dr. Kolmes references APA standards pertaining to the general principles and informed consent.

Conclusion

Although Dr. Kolmes' post pertains to a single product, Simple Practice, my concern is that other products will follow suit, if they have not already. Zoom originally released new Terms that were similar to those released by Simple Practice. After only a few days of receiving a rather large outcry of negative reactions, Zoom reversed their position and instead stated that Zoom healthcare products would be excluded from the new Terms. Simple Practice has made no such retraction. Other companies are mostly remaining mute – leaving me to wonder what I would find if I were to read the current Terms and BAAs of other healthcare software.

Obviously, those of us in healthcare professions have no control over the business decisions software companies make. However, our primary responsibility is, and always has been, to the patients, students, and other individuals we serve. However, the following guidelines may be useful:

- I still recommend using HIPAA Compliant Software that provides a BAA. However, read the BAAs. Don't just assume the company has your best interest at heart and sign. Although that might have been reasonable at one point in time, it no longer is.
- Integrated products such as EHRs may be better choices than stand-alone products, partly because you'll have fewer BAAs to try to make sense of and, thus, fewer potential loopholes.
- When feasible, use products that specify that they do not sell, barter, or trade any patient data, even in de-identified form.
- Special precautions should be taken with products that might use patient data to train AI models.

Unfortunately, I don't feel there are perfect solutions to this dilemma. Although it is possible to find products that do not de-identify and sell PHI, if you're already heavily invested in a product that does, it may be overwhelming to consider transferring to a safer product. APA's ethical standards require us to "take reasonable precautions" with patient confidentiality. The definition of "reasonable" is a decision each professional will need to make for themselves.

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