

The HIPAA Privacy Deception

Refuse to Sign the
“HIPAA Privacy Form”



Personal stories from real people
who have legally refused to sign the
so-called “HIPAA privacy form”

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Why Personal Stories?

Americans need to know the truth about the so-called “HIPAA Privacy Rule.”

CCH Freedom wants Americans to know that HIPAA does not protect patient privacy. In addition, Americans can legally refuse to sign the “HIPAA privacy form,” thus exposing the HIPAA privacy deception and refusing to further propagate the HIPAA privacy deception.

This document of personal stories of patients who refused to sign the HIPAA privacy form is part of CCH Freedom’s “Refuse to Sign HIPAA” campaign. Citizens’ Council for Health Freedom is using this campaign to highlight the fact that the “HIPAA Privacy Rule” does *not* protect patient privacy – and that patients are not required to sign the so-called “HIPAA privacy form.” Most clinic and hospital staff do not understand these facts and rights, and some have wrongly denied patients access to medical care for exercising their legal right to refuse to sign the form.

Here is what usually happens: When you enter your doctor’s office or the hospital, the person sitting at the desk will ask you to sign the “HIPAA privacy form.” It may be a separate form. It may be part of a bundled consent form — we call this *coerced consent* because it’s a single piece of paper with consent for treatment, billing, research, HIPAA and more all bundled together on one form with only one signature line. Sometimes there are boxes to initial or check for the separate items, but the question related to each box may be confusing and may lead patients to indicate consent when they intended to refuse consent. Sometimes there are no boxes. Regardless, most patients dutifully sign the HIPAA form. If patients refuse, management may be called in or patients are told no treatment can be given or they’re told they must pay cash although insured.

Signing the form leaves most patients with a false sense of personal and medical privacy.

Nothing about the HIPAA form protects patient privacy. The patient’s signature on the form only indicates that the patient, or the parent of the patient, has been given or read or understood — or any combination of the three — the clinic or hospital’s Notice of Privacy Practices (NPP).

But the NPP typically describes the broad sharing of the patient’s confidential demographic, medical and genetic information allowed without their express written and informed consent. For example, their confidential data can be shared for 12 “National Priority Purposes.” It can be shared for “payment, treatment and health care operations,” a trio of terms that encompass more activities than most patients would ever imagine. It can be shared for research, for government oversight, for public health surveillance, for law enforcement, for organ procurement, for national security, and much more -- all without patient consent.

According to an August 2010 federal regulation (1), because of the HIPAA rule and a 2009 law, the *Health Information Technology for Clinical and Economic Health Act (HITECH)*, enacted as part of the American Reinvestment and Recovery Act of 2009 (ARRA, Recovery Act or “economic stimulus”), **more than 2.2 million entities** have access to private patient data without the express written and informed consent of the patient, or the parent or guardian of the patient.

In short, HIPAA is a *disclosure* rule, not a *privacy* rule. And the NPP is actually a notice of disclosure practices, rather than a notice of privacy practices.

The NPP and the request that patients sign the “HIPAA form” are required by the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the HIPAA “privacy rule,” officially titled, *Standards for Privacy of Individually Identifiable Health Information*. (2)

The Rule became effective in April 14, 2001 with compliance by clinics, hospitals, health plans, and others required by April 14, 2003. It was amended four times between May 2002 and April 2003. Minimum penalties begin at \$100 per violation with maximum penalties of \$50,000 per violation. The annual maximum penalty is \$1.5 million in each of four violation categories. (3)

But HIPAA has no patient consent requirements. All patient consent requirements for sharing patient data were initially eliminated by the Clinton Administration. But a majority of the more than 50,000 public comments on the proposed HIPAA Rule requested consent requirements. The administration added consent requirements in the final rule, but only for “payment, treatment and healthcare operations.” These consent requirements were subsequently eliminated by the Bush administration in response to the requests of health plans and others in the data industry.

According to the U.S. Department of Health and Human Services, consent was eliminated because: *“The consent requirement created the unintended effect of preventing health care providers from providing timely, quality health care to individuals in a variety of circumstances. ...To eliminate such barriers to health care, mandatory consent was replaced with the voluntary consent provision that permits health care providers to obtain consent for treatment, payment and healthcare operations, at their option, and enables them to obtain consent in a manner that does not disrupt needed treatment.”* (4)

Patient consent was a Standard of Practice before HIPAA. Physicians and others who shared confidential patient data without patient consent could be sued. Eliminating consent requirements opened the doors to computerizing medical records (electronic health records) without consent and making the data in them widely available through state health information exchanges (HIEs) and the National Health Information Network (NHIN), now called the eHealth Exchange.

HIPAA’s permissive sharing of data also paved the way to the expensive and intrusive HITECH mandate that every physician and hospital purchase, install and “meaningfully use” electronic health records (EHRs). “Meaningful use” requires data sharing with government agencies. At CCH Freedom, we say, **“He who holds the data makes the rules.”** Government agencies, corporate health plans and Obamacare ACOs (hospitals with employed or contracted physicians) will more easily tie the hands of physicians through data-mining, tracking of treatment decisions, and financial penalties for physicians that choose to provide individualized care instead of following standardized one-size-fits-all insurer and government treatment and rationing protocols.

The “HIPAA privacy form” is a ruse. The form, along with the Notice of “Privacy” Practices, were mandated to deceive the American public into believing that HIPAA protects their privacy. It worked. Most Americans today believe HIPAA protects medical privacy. They are wrong.

To help CCH Freedom expose the privacy deception, please refuse to sign the HIPAA form.

Clinics and hospitals are required by the HIPAA Rule to “make a good faith effort” to get you to sign the form (2, p. 33), but you can refuse. The federal government has a special web page telling doctors, clinics, and hospital staff what to do when you legally refuse to sign the form. (5)

By not signing the form, you exercise your legal right to refuse to sign the form or to perpetuate or participate in the government deception called the “HIPAA privacy rule.”

Refusing to sign the HIPAA form also means the hospital and clinic will not be able to wave the form under your nose and blame *you* for sharing confidential information with them that you didn't want shared. They will not be able to say that you acknowledged (with your signature) that you read the NPP and thus knew that your confidential data could or would be broadly shared.

IMPORTANT NOTE: Refusing to sign the HIPAA form does *not* protect your privacy. Your confidential data can be shared with or without your signature on the form. HIPAA gives permissive authority to share and access data. Doctors, hospitals, health plans and others are not required to share your data, but by law (HIPAA) they can do so without your written consent. Again, the HIPAA “privacy” form is simply meant to convince you that you have privacy when you have none.

RESTORE YOUR PRIVACY RIGHTS:

- Don't sign the HIPAA privacy form. Expose the HIPAA deception as broadly as possible.
- Tell us what happened when you refused. **Share your story at HIPAAhurtme.com**
- Ask your state legislator to pass a law repealing all state privacy laws that “conform to HIPAA.” as well as a law that mandates written patient consent for sharing your medical data and for making your data available through a health information exchange. **NOTE:** HIPAA allows stronger, more protective state privacy laws to supercede the NO-privacy federal HIPAA rule.
- Ask your members of Congress to repeal HIPAA, to rescind the HIPAA rule, to defund state health information exchanges, and to repeal HITECH and the EHR mandate.

CCH Freedom has created a **wallet-sized card** for you to share with your clinic and hospital. It includes a URL for the HHS website that tells staff what to do when you refuse to sign. You can just hand it to the staff. They can look up the website online (bit.ly/HIPAAnotice) or take a copy of the card. **Contact us online, by email or by phone to ask for this card.** You can also find more information on our special web page: **TruthAboutHIPAA.org**

FOOTNOTES:

(1) “Proposed Changes to Privacy Rule Won't Ensure Privacy,” Health Freedom Watch, Citizens' Council for Health Freedom (Institute for Health Freedom), September 2010, Accessed November 19, 2014: <http://forhealthfreedom.org/Newsletter/September2010.html#Article3>

(2) “Standard for Privacy of Individually Identifiable Health Information, Security Standards for the Protection of Electronic Protected Health Information, General Administrative Requirements Including, Civil Monetary Penalties: Procedures for Investigations, Impositions of Penalties, and Hearings,” Unofficial Version of [Combined] Regulation Text (45 CFR Parts 160 and 164), U.S. Department of Health and Human Services, December 28, 2000 as amended: May 31, 2002, August 14, 2002 February 20, 2003, and April 17, 2003. Accessed November 18, 2014: <http://www.hhs.gov/ocr/privacy/hipaa/news/2002/combinedregtext02.pdf>

(3) “HIPAA Violations and Enforcement,” American Medical Association, n.d., Accessed November 19, 2014: <http://www.ama-assn.org/ama/pub/physician-resources/solutions-managing-your-practice/coding-billing-insurance/hipaahealth-insurance-portability-accountability-act/hipaa-violations-enforcement.page?>

(4) “Why was the consent requirement eliminated from the HIPAA Privacy Rule, and how will it affect individuals' privacy protections?” U.S. Department of Health and Human Services website, Last updated 11/9/2006, Accessed November 18, 2014: http://www.hhs.gov/ocr/privacy/hipaa/faq/privacy_rule_general_topics/193.html

(5) “Notice of Privacy Practices,” Health Information Privacy, U.S. Department of Health and Human Services webpage, n.d. Accessed November 19, 2014: <http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/noticepp.html> [or find at bit.ly/HIPAAnotice]

Signed and Revoked

In 2011, I took my children for dental cleanings. I declined to sign their “Consent to Arrange for Payment and Release Information”, explaining that I would be happy to sign any statement accepting responsibility for billing, but I was not required to release any information and declined to do so. They insisted I must sign or they would decline to do the cleanings.

I wrote out a proposed statement, with my signature and date, giving consent for sharing information for billing purposes, with my son’s medical record number and name. That was apparently not good enough. I also offered to sign if I could alter the text of the form. Again, that wasn’t good enough. This, though the form says at the bottom “I understand that I may revoke (cancel) this consent, in

writing, at any time.” Since I had all 3 children scheduled at one time, and school started in 10 days, I signed the forms and will now write and send revocations and take it up by telephone with “corporate,” the supposed source of all this intransigence.

My recollection of events of 8/16/11, when my three children arrived for dental cleanings:		I was asked to sign the Consent/Release and replied the law did not require me to sign it.	
Reception:	You must sign it or we can’t treat your children.	Reception:	(Took my writing to the dental clinic manager, returned to respond): No, the form can’t be altered in any way.
Me:	But you can’t make treatment contingent on signing it; you only have to ask me to sign it.	Me:	Why can’t I sign something that says you can share information for billing, but nothing else?
Reception:	We’ve recently had meetings and been told we must get the signature or we can’t give treatment.	Reception:	I’m very sorry, but that’s just our policy.
Me:	All right, I’ll write out my Consent/Release (wrote consent to treat and to disclosure for billing purposes only, with son’s name and MRN, signed and dated).	Me:	(Signed, deciding to revoke ASAP.)

The next day, I spoke with the dental clinic manager, explaining that my research suggested they cannot make treatment contingent on signature of Consent/Release. At some point in this conversation, the clinic manager must have explained that I could have paid up front and then not had to sign, because later in the day I called to ask her, ‘what

would happen if I send in my revocation before they’ve made their billing claim?’ She said she didn’t know, but would check with the Privacy Officer to whom she had already sent inquiries regarding my questions about why HP thinks it could do this.

After my initial visit and conversation with the clinic

manager, I had a telephone conversation with the clinic Privacy Officer and I was told that the clinic cannot and will not combine the various releases into one form that can be altered. It was also reiterated that clinic policy dictates that the form must be signed or the patient will be required to pay up front.

(continued page 10)

When I asked why the clinic could not separate the billing from the other releases, I was told, “well, it would just be too difficult and expensive to guarantee a patient their information will be used only in certain ways...it’s a business decision since so many people don’t want to sign more forms than they have to...”

How hard could it be to give patients like me, who don’t mind an extra form, the option to sign a billing only consent? I was told that across 2.5 million claims, it

would “end up being a lot of extra overhead.” I was also essentially told that I should just trust the clinic’s information management and that I should not worry about vague phrases like “quality care review studies” and “other functions.”

Regarding the original incident and the pressure to sign the HIPAA form, I see that the law clearly states that a good faith effort is required. Is there anywhere where the law says they may not do more than make a good faith

effort—that is, are they prohibited anywhere from requiring me to sign? My fear is that [the clinic] will argue they are permitted to require the signature either as fulfillment of HIPAA or simply as a private contract requirement.

Georgia

Minnesota, 2011

Tried to Refuse to Sign

Several years ago I looked at the CCHF website and have kept it as one of my “favorites.”

After reading about HIPAA, I have tried to not sign these forms anymore. My Endodontist forced me to prepay (rather than wait

for my insurance company to pay and then we do the difference) since I wouldn’t sign. I was then reimbursed from my insurance company.

Recently, I took 2 children into Woodbury, MN to see an oral

surgeon about wisdom teeth extraction. I refused to sign the HIPAA form. She called the administrator; they asked me to sign at the top of each form (one for each child) but I refused. Instead, I signed my name, dated it and put down “refuse to sign”.

Jennifer

Minnesota, 2012

Clinic Was Unaware of Patients’ Right to Not Sign HIPAA Forms

In 2012, I took my daughter to a counseling office for the first time. When presented with the HIPAA form, which I realize that they are required to present to me by law, I told them that I did not sign it on principle. They looked at me like I had green skin! They were shocked. The receptionist had to

check with someone else as to what they did with patients who refused to sign.

They did not force me to sign, but they also did not understand why I wouldn’t want to “protect myself.” I told the receptionist to check out CCHF on the web.

I was shocked that they wouldn’t be aware of the right to not sign, and the many reasons why I wouldn’t want to.

Shari

Minnesota, 2013

Why People Cave In and Sign

I had an incident where I was in a new clinic for me. I was feeling very ill, and my husband was along with me. I was told I couldn't be seen until signing the HIPAA form. I said I wasn't going to sign and they said they wouldn't treat me. I was then put on the phone while

hacking my lungs out to talk to the lawyer or business manager. After going round and round about them only having to make a good faith effort, and her telling me she was very uncomfortable with me not signing and that this was just the law, I held my ground and they

did treat me. She did mention that I wouldn't be able to this in the future. They did make me sign a consent form to be treated. Should people coming into a clinic really be told they are wrong and need to sign? I can see why people just cave in.

April

Minnesota, 2014

HIPAA Runaround

My family has had the same health insurance for over ten years. The medical care is great, but the corporate culture is poor. Specifically, for years this company has insisted on me signing a consent to treat/HIPAA release that is far too broad, at times *requiring* it to be signed before care will be given.

The latest frustration with this company's privacy practices arose out of my son's visit to a clinic in January 2014. When I objected to the release, the receptionist said I could complain to a certain office and handed me the "Notice of Privacy Practices." When I told her I would be revoking the consent she did not offer me a photocopy of the release nor did she provide me instructions for how to do that.

Naturally, then, I was annoyed when I found the Notice of Privacy Practices said nothing about how to revoke the execution of consent to treat. It took at least 6 employees before I found one who could tell me what had to be done. The last employee took my address so that she could send me a revocation form. When it arrived, I found its blanket language gives me no option other than revoking my consent to any and all disclosure of medical records.

Why doesn't this company revise its consent/HIPAA release to let patients allow the minimum level of disclosure necessary for billing and coordination of care, but not the wildly overbroad release demanded by the current form?

Unfortunately I know why, because over two years ago I spoke to the company's Privacy Officer by telephone on the matter and he admitted it was purely for the sake of corporate efficiency: "That would be a lot of trouble and overhead," he said. The company persists in making it impossible for patients to choose more than one level of disclosure.

Patients should be able to both enjoy the benefits of their coverage and keep the maximum privacy consistent with settling claims.

Debbie

Texas, 2012

Sign or No Surgery

I read CCHF's HIPAA press release from May 8, 2012. When I had to go in for shoulder surgery in late 2012, I refused to sign the

HIPAA forms and cited CCHF, and even directed the hospital staff to CCHF's materials.

The office manager stated that office policy was that a patient had to sign the form in order to get the procedure, so I reluctantly signed.

Jeff

2013 & 2014

Twice Refused for Not Signing

I have two personal experiences of refusal of service due to my refusal to sign their HIPAA agreement forms.

One experience was at a dental office in the summer of 2013, and the other was at a Chiropractor's office in January 2014.

In both cases I was a cash customer and was asked why I did not want to use my insurance. I explained, both times, that there is a deductible that I have to cover before the insurance pays a dime. In order to streamline the mailing/billing and payment process I eliminate the middle man and pay in cash, keeping the receipts in the case that I might some day pay the full deductible and need insurance coverage.

I explained to both offices that they do not have to wait for months before getting paid while the insurance company wastes time sending letters to confirm services and charges. I also explained that I do not like being threatened with collections prior to insurance paying their share or determining that they do or do not cover said service.

In both cases I received paper work asking about personal non-related events/activities and personal preferences that I refused to divulge. I also received HIPAA agreement forms that I refused to sign.

In both cases, the receptionist told me that it was the LAW and that I had to sign the HIPAA

agreement. It was for my own protection. I explained that the form was not for my protection but for the insurance companies, state and federal governments and their own businesses protection as they were using my personal information for their own purposes. I informed them that I would sign a non-disclosure agreement permitting the release of my personal information and records with my explicit consent only so that I can keep abreast of who is requesting and accessing my information and for what purpose.

I was informed that I would be the 'first in history' to not sign the agreement.

I was told both times that the form was just a simple acknowledgement of being offered the official HIPAA pamphlet. The forms in each circumstance stated that by signing the HIPAA form I agreed to/accepted the insurance companies, MN state, federal and individual businesses privacy collection, disclosure, terms and use policies.

In response to my refusal, the respective owner/operators of both offices got upset and ranted about money and time spent educating staff, licensing requirements, reports to HHS and possible loss of licensure if I did not sign their HIPAA agreement. I was informed that I would be the 'first in history' to not sign the agreement.

In each situation I could not help but laugh and explain to them that I was literate and could read. I also explained that I did not care for or condone the collection, distribution and use of private information for insurance, corporate, state and or federal gain or control. I was told that they agreed with my statements. However, both stated that they still needed me to sign the HIPAA form.

In both cases I asked how they benefited from having me sign the HIPAA form and was met with a long silent non-response and frustrated look. Finally, both offices told me that service would not be provided until I signed the HIPAA agreement form.

In the case of the Dental office, I simply refused to sign and walked out.

In the case of the Chiropractor, I requested any other non-disclosure form they had. I was presented with 3 forms all relating to HIPAA. One about cash customers & HIPAA, one on insurance and HIPAA and finally the one I signed and dated that declared to rescind any and all HIPAA forms on file.

It seems that neither one of these practitioners were concerned with patient-doctor privilege and/or basic respect. Both seem more interested in keeping their insurance business and apparently state license to whatever extent possible.

Debra

New York, 2013

Blood Oozes During Standoff

My husband came home from work early one morning. He had a right index finger laceration and was bleeding heavily. We got it bandaged and wrapped and drove to the nearest emergency clinic where we waited about 10-15 minutes to be called for registration. When we were called up, we were given the usual paperwork.

It was then that I told the receptionist that we do not sign HIPAA forms. She said it was required and that they would not be able to treat if not signed. I explained that was not the case and suggested she go on the HIPAA site and look for herself that it was not required. (I explained why.) I told her that they should have a refusal to sign form for patients if needed. She had no clue as to what I was talking about. She said she would ask the Doctor if he would treat.

She returned and said that the Doctor would not treat without us signing the HIPAA form. All the while my husband was in serious pain. I explained again why this was in violation of the HIPAA law and that signing or not signing

had no bearing on treatment. She asked why we would not sign and I explained the reason yet again. She insisted that they are very strict with medical records and privacy and that they were not "federal". Obviously, she had no clue.

The Dr. would not treat without us signing the HIPAA form.

All the while, my husband was in serious pain.

She then called the main office and spoke to "someone". I was then told that the "someone" was going to contact their legal department and we were instructed to sit in the waiting room.

We waited for at least another 20 minutes before she came to us and said that we would not be seen. The Dr. could look at it if we wanted but would not treat it – they would then send us on to a hospital emergency room. We were told we must sign the HIPAA form. By this time I was outraged, my husband was in pain and the blood was now going through the

bandages.

She said we must sign the HIPAA and treatment/ financial agreement. I told her I had no problem signing the treatment/ financial agreement but NOT HIPAA. She said she was sorry, but they could not see us. I demanded all the paperwork she wanted signed. I told her she needed to educate herself (since she wouldn't listen to me).

We left and went to another clinic about 10 miles away. We signed in and were called back for triage. They took him back right away even before registration and treated him immediately while I registered. This time the HIPAA form had a "refusal to sign" box that I checked. NO PROBLEMS.

When I got home I called the HIPAA compliance officer of the first clinic. He asked me to explain what happened. I did. I was shocked that he was not the one the clinic called. He apologized over and over and said a lot would have to change from there on out. He was going to look into the matter further and that he would have the "higher ups" call me.

Diana

Indiana, 2014

We Chose to Leave

My husband and I recently went to get our eyes examined. We were told that if we didn't sign the HIPAA form, that we would have to pay out of pocket for our eye exams and glasses, even though

we had insurance to cover the costs. We chose to leave. Later that day, we received a call stating that they had been wrong. We went elsewhere where no HIPAA form was required. Thanks for

all you do. If we had not been educated on the truth of this matter, then we would have been forced to sign.

Jan

Minnesota, 2011

Successfully Refused Once

I went to a clinic to treat an infection and, when presented with the HIPAA forms, I told [the clinic staff] that I understood I did not have to sign the forms.

They said I had to sign the forms or they could not see me. I left the clinic because I was not going to sign. I sought treatment elsewhere and did eventually sign the form to receive treatment.

I later returned to the first clinic

for an annual physical and had more information with me about not having to sign HIPAA. When I received more forms I asked [the clinic staff] what part was HIPAA, they told me I only needed to sign for treatment and release of records to the insurer.

I crossed off “research” and I have received a copy of their Notice of Privacy Practice (NPP). I then signed the form. They did not object at the time.

I later went to West Health for a mammogram. This time, the staff said I had to sign the HIPAA form. There was a bottom paragraph about Electronic Health Records (EHRs) below the signature, and I had to write out “I object to this paragraph.” Because I did that I was asked to sign another paper requesting confidential security features including a “break the glass” feature, which gave them access to my data without consent in an emergency.

Brenda

2012

Endangered by Data Sharing

I was told two things while at the doctor’s office while having a conversation with the doctor himself:

1. That I need to sign the HIPAA agreement. Because of your information on the site, I knew that I could stand my ground, Thanks.

2. My bigger problem is that I told him that I would not allow my medical records to be in EMR’s. He said that I would not get a doctor to treat me because everything is going electronic, and that no doctor will accept the government fines over a patient.

What I feel it comes down to is that I will not give information to a doctor that I do not want shared.

Even to my detriment because I feel so strong about the subject. Nor do I go to a doctor unless I really need to go and I never let them weigh me. I know that I am cutting off my nose to spite my face, but I am not going to share any information with my doctor that I don’t want shared. There must be others that feel the same way I do but feel powerless to do anything about it.

Jan

Missouri, 2014

The Silent Treatment

My husband went for a colonoscopy and he informed them upfront that he refused to sign the HIPAA form and told the doctor that he should tell me, the wife, everything. The Doctor agreed.

Every phone call thereafter, the staff REFUSED to speak to me, and made a point to say OVER AND

OVER, “it is your choice to not sign, but we will not speak to you.”

After speaking to the clinic supervisor, she said she was bound by law and really had no control in the matter. I requested a call from the physician himself, which did not happen.

On the day of procedure, I was asked if he would sign, or we would not know the results of the testing until a follow up appointment, which is usually not necessary.

My husband decided to just sign ‘the thing’ and get this over with.

