



**CCHF Presentation to U.S. Senate Health, Education, Labor, and Pensions (HELP)
Committee *Privacy Working Group*
Prepared Remarks by Twila Brase, President and Co-founder, CCHF
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Why CCHF Opposes a National Unique Patient Identifier

Thank you for inviting me to share our organization's perspective on the Unique Patient Identifier. My name is Twila Brase. I am a registered nurse, who once specialized in pediatric emergency room nursing, and I am the president and co-founder of Citizens' Council for Health Freedom (or CCHF), a patient-centered, privacy-focused, free-market health policy organization based in St. Paul, Minnesota.

To acquaint you with our organization, and me I'd like to start by sharing a few things about myself and several accomplishments and issues central to CCHF.

I'm pleased to say that I was recently selected from more than 300 applicants to be one of 18 participants in the **HHS Quality Summit**, co-chaired by Deputy Secretary Eric Hargan. And I am the founder of **The Wedge of Health Freedom**, our online directory of direct-pay practices, which seeks to bring cash, check, or charge patients and doctors together, outside of government, insurance and costly third-party interference. Find it at *JointheWedge.com*

Our organization, **Citizens' Council for Health Freedom**, began in 1998, but the precursor organization to this one, which I also co-founded, was founded in 1994. So I have been engaged in this work for 25 years.

We work on both state and national health freedom issues—for example, we worked for three years to give seniors the freedom to opt out of Medicare without losing their Social Security benefits. That option is in **President Trump's October 3, 2019 executive order**.¹

And we are well known around the country for our work to protect patient medical and genetic privacy rights. An anonymous letter kick-started our work on privacy and we've been at it ever since.

Let me share some examples. We have a longstanding national public awareness and engagement campaign that calls on Americans to refuse to sign the HIPAA form or the HIPAA Notice of Privacy Practices acknowledgement statement. (*HIPAAhurtme.com*)

¹ "Medicare Executive Order on Protecting and Improving Medicare for Our Nation's Seniors," President Donald J. Trump, October 3, 2019: <https://www.whitehouse.gov/presidential-actions/executive-order-protecting-improving-medicare-nations-seniors/>.

There's no law requiring patients to do it and signing the form perpetuates the myth that the federal HIPAA "privacy" rule protects privacy when it does the exact opposite. The HIPAA rule is a permissive data-sharing regulation that has dismantled patient consent requirements. Just read your clinic's Notice of Privacy Practices at your next appointment.

I am also the author of several privacy-focused reports, including reports on:

- State health surveillance systems in all 50 states
- Newborn genetic screening and state storage and use of newborn DNA
- Birth certificate data-collection
- Patient stories related to refusing to sign HIPAA
- The advance of biometric IDs in the U.S.
- National Patient ID.

The 2012 National Patient ID report is in your packet.

I am also the author of a four-time award-winning book we released last year called: ***"Big Brother in the Exam Room: The Dangerous Truth About Electronic Health Records."***²

This book has more than 1,500 endnotes, and within the "HIPAA Doesn't Protect Privacy" section, there is a chapter called "National Patient ID," starting on page 179.

Now to the question of the Unique Patient Identifier:

One of the things our staff frequently tells the American public is this: **"He who holds the data makes the rules."** He who holds the data makes the rules.

Surveillance is and has always been a tool of control. In the case of HIPAA, government-certified electronic health records imposed on patient and their physicians, and national identifiers, this surveillance means the control of physicians and their medical treatment decisions.

Our opposition to the Unique Patient Identifier began with the Administrative Simplification section of the 1996 Health Insurance Portability and Accountability Act, otherwise known as HIPAA.³

It didn't take long before we discovered that the four national Identifiers in HIPAA (the Employer Identification Number (EIN), the Health Plan ID (HPID), the National Provider Identifier (NPI), and the Unique Patient Identifier (UPI) were first proposed in the 1993 Clinton Health Security Act,⁴ which was a bill to nationalize the American health care system. (*See section 5104.*)

² Find it at: BigBrotherintheExamRoom.com

³ H.R. 3600, U.S. Rep. Dick Gephardt, November 20, 1993:
<https://www.congress.gov/103/bills/hr3600/BILLS-103hr3600ih.pdf>.

⁴ Ibid.

President and Mrs. Clinton's bill included these four identifiers, *and* a national electronic medical records system (*section 5101*), *and* a national "health care security card" embedded with the unique patient identifier (*section 5105*).

On September 22, 1993, I watched President Clinton as he held up a prototype of that card before a national television audience.⁵

The Clinton's national health care bill made clear the connection between a national health care system and a national health data system.

It stated, "the National Health Board shall develop and implement a health information system by which the Board shall collect, report, and regulate the collection and dissemination of the health care information described in subsection (e)..." which included such information as enrollment, clinical encounters, services received, and financial and administrative transactions.

The Clinton's national health care bill also included government-issued "**practice guidelines**" for doctors to follow and required performance and quality measurement reporting to monitor the physician's compliance with those treatment directives. (*Section 5006*)

The Clinton Health Security Act specified that the National Health Board had to **establish the purposes for which a unique patient identifier could be used** (*Section 5104*). Furthermore, the unique identifier numbering system had to be used to encode identification information on each American's National Health Security Card, including their unique patient ID and their Health Plan ID (*Section 5105*). The only permissible uses of the card were providing or assisting patients to obtain medical care. **Therefore, no card, no care.**

So to be clear: The Clinton's proposed national health *information* system was key to establishing their proposed national health *care* system, and the four national identifiers were key to establishing the national *information* system that would run the national *care* system. Thus, they proposed a socialized medicine system controlled through identifiers, a national medical records system, government surveillance, a government-issued access card—and practice guidelines.

Altogether, the four national identifiers and the national health information system for tracking every treatment decision, every patient diagnosis, and every moment of compliance or non-compliance with the Act's government-issued practice guidelines would give the federal government control over the entire health care system.

That meant every physician, every practitioner, every hospital, every health plan and patient's access to every medication, medical procedure, and medical device.

Two years after the Clinton bill failed, in 1994, **HIPAA**, the Health Insurance Portability and Accountability Act of 1996 **became law**.⁶ It includes the Clinton's administrative simplification

⁵ "CLINTON'S HEALTH PLAN; Transcript of President's Address to Congress on Health Care," September 23, 1993: <https://www.nytimes.com/1993/09/23/us/clinton-s-health-plan-transcript-president-s-address-congress-health-care.html>.

language. It includes the four national identifiers, and it too says its purpose is to encourage “the development of a health information system” (*Section 261*).

Two years later, in 1998, I testified at the first of several scheduled Unique Patient Identifier hearings to be held by the National Committee on Vital Health Statistics.⁷ This hearing took place in Chicago. A *New York Times* reporter attended the hearing, which was discussed in detail the next day on the front page of the *New York Times*. That ended the UPI hearings. The rest of the hearings were cancelled, never to be rescheduled.

Shortly thereafter, **Congressman Ron Paul added a prohibition** to the 1999 appropriations bill to prevent the funding and development of the Unique Patient Identifier. He annually added the language banning the UPI from development until he retired in 2013.

Notably, in 2008, The **Rand Corporation decried** the lack of progress toward a national unique patient ID saying, “Unlike almost all of the other governments, Washington is not developing a unique patient identifier to use as a singular key to accurately link, file, and retrieve individual health records.”⁸

Note the terminology: “a singular key.” That is the plan.

The Rand Corporation also bemoaned the privacy concerns that had arisen over networking patient data beyond local health care data systems. That too is the plan: a single nationally networked nationwide data system. All patient medical records – from womb to tomb – accessible under a single number, with no patient consent required, as permitted by the federal HIPAA rule.

After HITECH was enacted in 2009 (as part of the American Recovery and Reinvestment Act (“economic stimulus”)),⁹ which imposed government-designed electronic health records on all doctors and hospitals on pain of penalty, the health care and data industry began anew their push to convince Congress to impose a national patient ID.

In the appropriations bill, signed in May 2017 with Congressman Ron Paul no longer in office to oppose the move, **the ban was softened** by allowing federal officials to work on developing a “national patient-matching strategy.” Proponents of a National Patient ID cheered in new stories; they understood what this meant.^{10,11}

⁶ Public Law 104—191—August 21, 1996 (Health Insurance Portability and Accountability Act of 1996): <https://www.govinfo.gov/content/pkg/PLAW-104publ191/pdf/PLAW-104publ191.pdf>.

⁷ “Hearing Minutes,” National Committee on Vital and Health Statistics, Subcommittee on Standards and Security, Chicago, Illinois, July 20-21, 1998, <http://ncvhs.hhs.gov/980720mn.htm>.

⁸ “IDENTITY CRISIS: “Examination of the Costs and Benefits of a Unique Patient Identifier for the U.S. Health Care System,” Richard Hillestad, et al, Rand Corporation (“Sponsored by Cerner Corporation, CPSI, Intel, IBM, Microsoft, MISYS, Oracle, and Siemens”), 2008:

https://www.rand.org/content/dam/rand/pubs/monographs/2008/RAND_MG753.pdf.

⁹ “Health Information Technology for Economic and Clinical Health Act (HITECH), Section 13001, Title XIII, American Recovery and Reinvestment Act of 2009, P.L. 111-5, February 17, 2009:

[https://www.cchfreedom.org/files/files/ARRA%20GPO%20version%202011%20access\(1\).pdf](https://www.cchfreedom.org/files/files/ARRA%20GPO%20version%202011%20access(1).pdf).

¹⁰ “After Nearly Two Decades, a Win in Congress for Patient Data Matching,” Carla Smith, HIMSS, May 9, 2017: <https://www.himss.org/news/after-nearly-two-decades-win-congress-patient-data-matching>.

One possible “national patient-matching strategy” could be a National Patient ID, so funding and communication could begin, even though the 2017 appropriations bill still prohibited promulgation of a unique patient ID without specific Congressional approval.

Nearly two years ago, at the annual conference of HIMSS—*the Health Information Management Systems Society*—I heard Ben Moscovitch from Pew Charitable Trusts and John Halamka from Beth Israel Deaconess System co-present¹² on National Patient ID and other patient-matching strategies.¹³

During the Q and A, Ben Moscovitch relayed how he came up with the phrase. He essentially said the phrase “national patient-matching strategy” didn’t have the same **fear factor** as the term National Patient ID. In other words, it didn’t raise the same level of alarm.

But apparently the matching strategy is not working as well or as fast as proponents would like, or it’s not really what they want, because here we are today. **The U.S. House has passed an appropriations bill (June 2019) that lifts the ban on creating a National Patient ID**, thus moving to eliminate the one thing that stands in the way of establishing a national health data system and with it, a national health care system.

Two more items before I conclude. Whatever you may hear from the purveyors of the Unique Patient Identifier, it’s notable that even they say it won’t work to solve the issues for which they claim this number is needed. You can find a quote to that effect in **point #10** of my handout.

In addition, consider how Ben Moscovitch at Pew has written that the UPI could help ensure that people with the same name don’t get mixed up.¹⁴

Supporters of the **Social Security Number** probably claimed the same thing back in the 1930s. However, today, there are multiple people with the same SSN. In 2010, ID Analytics said there were **40 million Social Security numbers – that’s about 10 percent – associated with multiple people.**¹⁵

Early supporters of the Social Security number probably also claimed that it would not, in fact, could not, be used for any other purpose than to “uniquely identify U.S. workers” for the

¹¹ “National Patient Identifier Gains Congressional Support,” Kate Monica, EHR Intelligence, May 11, 2017: <https://www.himss.org/news/after-nearly-two-decades-win-congress-patient-data-matching>.

¹² HIMSS18 Recap,” Grace Koh, Verato, March 22, 2018: <https://verato.com/blog/himss18-recap/>

¹³ “The Need for a Nationwide Patient-Matching Solution,” HIMSS18, March 6, 2018, Recording available here: <https://www.himsslearn.org/need-nationwide-patient-matching-solution>

¹⁴ “The House of Representatives Wants a Unique Patient Identifier. Here’s What Should Happen Next.” Ben Moscovitch, Shaun Grannis & John Halamka, The Pew Charitable Trusts, July 31, 2019: <https://www.pewtrusts.org/en/about/news-room/opinion/2019/07/31/the-house-of-representatives-wants-a-unique-patient-identifier-heres-what-should-happen-next>.

¹⁵ “The Tale of Two Women: Same Birthday, Same Social Security Number, Same Big-Data Mess,” Kathryn Noyes, CIO, November 11, 2015: <https://www.cio.com/article/3004596/a-tale-of-two-women-same-birthday-same-social-security-number-same-big-data-mess.html>.

purpose of tracking earnings and providing retirement benefits.¹⁶ It was, in short, a “**Unique Worker ID.**” But today, according to the Social Security Administration, “the SSN may be the most commonly used numbering system in the United States.” The Social Security Administration says that the universality of the Social Security number has led to fraud and abuse.¹⁷

If a Unique Patient Identifier is adopted, expect a repeat performance such as we’ve experienced with the Social Security number.

So let me conclude this part of the presentation by saying this:

While privacy and hackers and the rest of our [10 items on our handout](#) are huge concerns with the UPI, and although the history of the Social Security number shows how a unique ID can turn out to be not so unique for many people and lead to fraud, what is ultimately at stake is most obvious in our handout under items **#1** (No card, no care), and **#8** (socialized medicine).

The real question is whether Congress is going to keep in place the one thing—the ban on the Unique Patient Identifier—that is stopping an unconstitutional, government-controlled care and coverage system from being fully implemented in America or whether Congress is going to facilitate the long-prohibited creation of the national health care system the Clinton administration pushed in 1993.¹⁸

Congressman Ron Paul, a physician and astute observer of history, recognized the danger of a National Patient ID from the get-go, and shut it down. Year after year, and appropriations bill after appropriations bill, Congress agreed with him.

Now **Senator Rand Paul** has wisely taken up the battle against the Unique Patient Identifier and the national health care system it would bring into being. And he has done his father one better. He has introduced **a bill to repeal the national Unique Patient Identifier** altogether.¹⁹

That is the right direction for Congress to take.

It is the only constitutionally sound direction. It also acknowledges the constitutional rights, human rights, and patient rights of Americans to not be under federal surveillance and control in the exam room.

¹⁶ “The Story of the Social Security Number,” Carolyn Puckett, Social Security Bulletin, Vol. 69, No. 2, 2009: <https://www.ssa.gov/policy/docs/ssb/v69n2/v69n2p55.html>.

¹⁷ Ibid.

¹⁸ It is notable that President Obama and the Democrat-controlled Congress also sought to establish outside access to patient data as the controlling foundation of the national health care system advanced by the Affordable Care Act. The 2009 enactment of the HITECH Act one year before the ACA was enacted, with its quasi-mandate for electronic health records nationwide and more than \$30 billion in funding for EHRs and state health information exchanges, was considered the “foundation” of the ACA. (Twila Brase, *Big Brother in the Exam Room: The Dangerous Truth About Electronic Health Records*, (Beavers Pond Press, 2018), page 9.)

¹⁹ “Sen. Rand Paul Introduces National Patient Identifier Repeal Act,” HIPAA Journal, September 27, 2019: <https://www.hipaajournal.com/sen-rand-paul-introduces-national-patient-identifier-repeal-act/>.

Thank you for inviting me to speak to you today.