

US National Digital Health ID It's already here!



ONC National Digital Health ID



US ONC is the Office of the National Coordinator for Health Information Technology



US ONC has launched the National Digital Health ID.



They have mandated all states to maintain a health information exchange (HIE).



An HIE is a cloud data system.

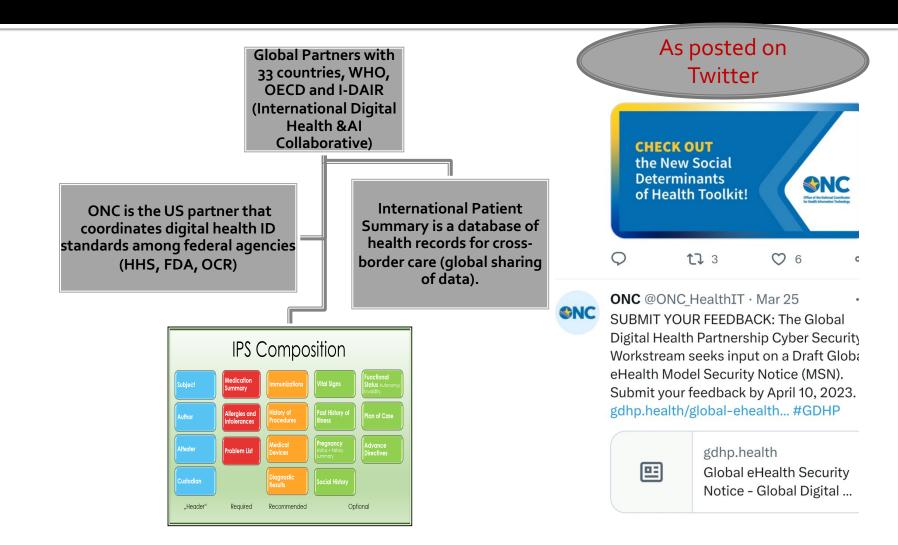


ONC can track SDOH (social determinants of Health) that include your neighborhood, job, income, hobbies, food, activities, education



All licensed healthcare providers and organizations are mandated to upload full medical records of all patients to the HIE.

ONC, Global Digital Health Partnerships & International Patient Summaries



Your medical records are valuable data

In a data driven world with privacy rights in the highlight, the capitalistic commercialization of our personal data is blending with government programs and policies.

Important decisions are being made by federal and state officials, commercial and technology industries (Apple, MS, CVS, Anthem, Pfizer, etc) with no nationwide public input.

ONC holds
"Datapalooza 2023"
with data scientists,
policy makers, health
care leaders,
entrepreneurs,
researchers, and patient
advocates.

It's a data party with your data but you're not invited.

No national citizen discussion, information or consent.

What about HIPAA?

 HIPAA provides minimum standards on privacy. Basically, it states records are private, with the following exceptions:

Exemption 1 When mandated to report for safety risks to self or others, including child abuse.

Exemption 2: With signed written informed consent that names who iis authorized to receive the information, what information, for what purpose with minimum assary.

Notice the number of issues being framed as "public health" matter. Guns, misinformation, loneliness, etc.

Exception 3. For public safety, public health risk, law enforcement, judicial proceedings, and as required by law.

Exception 4. To conduct business operations, utilizing a business associate agreement (BAA).. This usually involves office staff, billing, collections & accounting.

This is the loophole being used to bypass informed consent. Providers are mandated to have BAA with HIEs.

https://maloneinstitute.org/nationalid

Business Associate Agreement (BAA)

BAA is a contract for business operations. Office manager, biller, scheduler, accounting, insurers, collections, cleaning, legal defense. It is specific.



onc and States are mandating providers to sign a BAA with HIE, thereby having a business agreement that doesn't require informed consent.



Some states, including CT, have BAAs that state unless a citizen opts-out, their consent is assumed or not required.

What is Informed Consent?



Written or verbal (in emergencies) permission.



Authorization to release protected health information (PHI) to a specific provider, for a specific purpose, with the minimal necessary specific information.



BAAs for HIEs bypass citizens' informed consent, confidentiality and medical privacy rights.

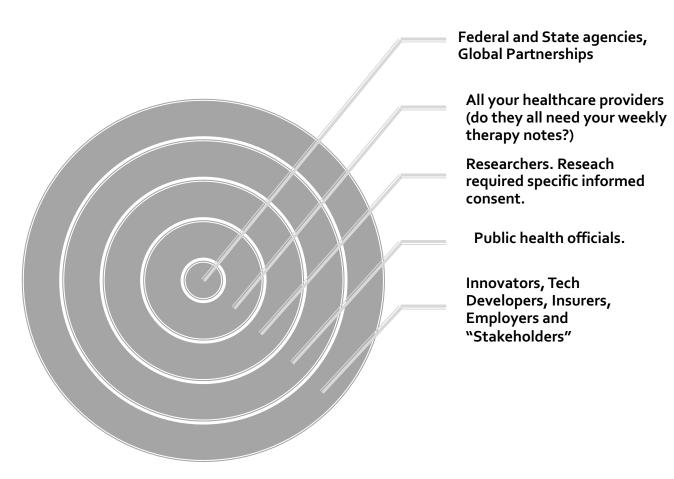


This is highly unethical and violates provider licensing requirements for confidentiality.

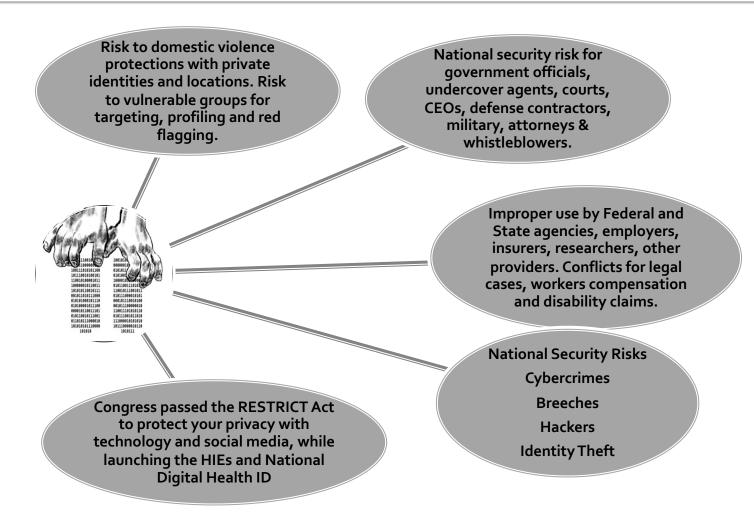


HIE won't inform who your data is released to, sold to (they call it "fees & cost shares"), how it's used, it's not minimum necessary, it's not requested, and not de-identified.

Who Gets Access



Risks for Digital ID and HIE



Mental health, substance abuse, HIV, domestic violence & sexual identity privacy laws.

ONC wants your therapy records, including notes, for every session in real time uploaded to HIEs.

There are protected groups that are given legal privacy protections that specifically require meaningful informed written consent

Mental health and substance use records must be exempt from HIEs. ~Mental Health
 ~Substance
 Abuse
 ~Reproductive
 Health
 ~Domestic
 Violence
 Survivors

~HIV

Despite these privacy protections, ONC has specific goal to capture Behavioral Health data.

ONC utilizes Al to Determine Quality & Analyze Data

Al will be used for clinical decision making (called Support) Al will determine treatment quality. If records are flagged by algorithms, individuals could be identified as a public health risk.











AI will be analyzing data.

How will this not be used for profiling and targeting under public safety notification?

ONC & JASON propose Al to capture healthcare data



Capture Smart Phone Data to support Al application



Integrate Social and Environmental data (social behaviors)



Support AI competition to support data generation and AI development.



JASON is an independent advisory group that offers consultation on defense, science and technology, including the DOD, NSA and FBI.

Al used for Identity Verification



Al and Biomarkers will be used to sign in to verify your identity, including fingerprint, facial scan, voice, iris scan and palm scan.



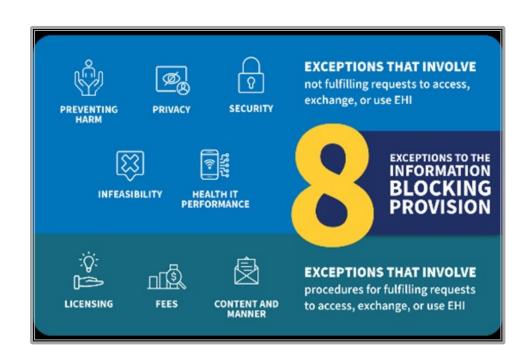
 Project US@ is identity matching with USPS.

USPS is partnered for identity matching history for all addresses, names, family members.



Information Blocking Penalties

ONC has current policy against information blocking & established penalties to eliminate "unnecessarily" restrictive data sharing practices.



Terms to Know



Standardized: medical record data would be standardized so everyone is using the same terms and definitions.



Interoperable: Means the HIE systems across all states and countries can communicate and share records with each other.
This is national and global.



Identity Proofing: Match and verify history of all your identification; names, addresses and family.



Providers may be required to use interoperable electronic health record software with standardized drop down menu click boxes to report data to the government

"It's all for your convenience"

Maybe have the HIEs to let people sell their own data for a fee & choose who they want to sell it to!

All records in one spot to share with providers (That no one requested)

Your rights to access (But not on the HIE; you will use Apple Health and other apps)

> It keeps your records safe (But it makes them less safe)

Can be used for a community record to keep you healthy; with data from your social & lifestyle data from criminal justice, housing and urban development, and other social support systems

> It keeps your records private (But shared & sold & data mined)

Removes the "burden" of informed consent. (But it's standard procedure among providers) Is Apple really where your private medical records belong?

Apple 🧼 @Apple Health data shouldn't be public. The Health app helps keep it private.



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CARIN Alliance Partnership

As posted on twitter

ONC @ONC_HealthIT · Apr 7 ····
ICYMI, check out this digital identity proof

of concept that our colleagues as part of @HHSgov's XMS team also contributed to.

The CARIN Al... @carina... · Mar 21

Announcing the results of our year-long proof of concept with @HHSGov @CMSGov @ONC_HealthIT to test approaches for establishing an open nationwide digital identity federation ecosystem.

Report --> bit.ly/3nbmWRj Demos --> bit.ly/3ltgAfq

Show this thread

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ONC has partnered with CARIN Alliance for National Digital Health ID. Their partners are:

Amazon, Apple, Google, Microsoft, Anthem, Cigna, CVS and other private, commercial groups.

Federal ONC, FTC, OCR, VHA, CMS, HHS, NIH

Big Picture on Federal Level

• 2016: Introduced HIEs & HIPAA. Their "Playbook" has been in the planning stages to develop policies and plans for National Digital Health ID for many years. They are now in the implement phase & acting on the plans.

 NIH states written informed consent is required for release of records, data sharing & conducting research.

 National Institute of Health programs & initiative are all data driven, including The Cures Act, All of Us, The Brain Initiative, Genome Research, Biosafety and Biosecurity. US Health and Human Services collects All-Payor Claims Database. It requires insurers to submit ALL claims from ALL providers to the State. That means they have access to claims from all providers, the diagnosis, date of service for every claim. There is a focus on mental health and substance abuse data as a high priority.

CURES Act



National Institute of Health (NIH)



Health & Human Services (HHS)



- The Constitution divides government power by addressing separate roles of powers: legislative power within Congress, executive power with the President and judicial power within the Courts.
- National Digital Health ID, privacy rights and data sharing are constitutional issues that need to be addressed among the legislature, and will allow citizen involvement.

Constitutional Separation of Powers



- FTC Act states HIPAA disclosures can not be deceptive. It requires written consent, plain language and specific terms and descriptions. It requires disclosures that specify the who, what, where, when and why of the sharing of health information.
- Digital Health ID & HIE does not specify who it will be released to, what it will be used for, why it's being used, when it will be shared.

Federal Trade Commission (FTC)



On The State Level

Almost all states already have an HIE that healthcare providers are uploading medical records to. Healthcare insurers are also sharing records to the exchange, including Anthem and Cigna, with no informed consent from consumers. To see information regarding your state's HIE, go to:

https://www.healthit.gov/sites/default/files/State%20HIE%20Opt-In%20vs%20Opt-Out%20Policy%20Research_09-30-16_Final.pdf (from 2016)

For example, Connecticut's HIE is Connie Exchange. CT assumes consent, unless you opt-out. But no one knows about the HIE. They only know they can see their charts and labs now (so can everyone else). In 2022, all hospitals and large organizations (ex: Quest, CVS) started sharing full medical records to Connie. In 2023, private practice and small organizations are mandated to share full medical records. Currently, mental health providers are refusing to comply with the mandate due to privacy laws, including CGS Sec. 52-1460:

"Disclosure of patient communication or information by physician, surgeon or health care provider prohibited." To learn more or to opt-out, go to https://conniect.org.

Red Flags



Take Action Now

