



Resiliency, Interoperability, and Health Data Governance

Tara R. Holiday, JD, MPH
VP, Legal at b.well Connected Health

Prepared for the Forum on Medical and Public Health Preparedness for
Disasters and Emergencies, Workshop on Data for Situational Awareness
National Academies of Sciences, Engineering, and Medicine



Assistant

I found a pulmonologist 4.2 miles away with the earliest opening Thursday at 10:30 AM. This visit is covered under your plan.

Would you like me to book it?

Yes, book it.



Where We're Headed

- 01 Why data governance matters — and what determines its scope and success
- 02 The legal foundations for sustainable data governance
- 03 What resilient data governance looks like
- 04 When peacetime rules meet emergencies: the legal switches
- 05 Four case studies where governance was tested by crisis
- 06 How to build governance that holds — for agencies, organizations, and the public

Why Data Governance Matters — Who It Serves

Who It Serves

- 1 Patients & families (access, accuracy, control)
- 2 Clinicians & care teams (trusted data at the point of care)
- 3 Public health agencies (situational awareness)
- 4 Researchers & innovators (safe, meaningful secondary use)
- 5 Payers & health systems (compliance and efficiency)

What It Reliably Delivers

- 1 Interoperability across systems
- 2 Data quality and trust
- 3 Privacy and security assurance
- 4 Equitable access
- 5 Auditability and accountability

What Determines Scope, Impact, and Success

- 1 **Clearly articulated goals** — a federal agency, a health system, and a platform company see mission and risk tolerance differently
- 2 **Legal authority** — who can controls data sharing versus who can only convene and recommend
- 3 **Data scale, diversity, and speed** — real-time, real-world data behaves differently than periodic reporting
- 4 **Organizational maturity** — councils without durable mandates don't survive past the crisis that created them
- 5 **Public trust and transparency** — governance that isn't visible to the people it protects rarely earns lasting legitimacy

HHS Federal Open Data Infrastructure

The department defines data governance as “a service and communication tool to engage with HHS data leaders in the creation and adoption of data policies, standards, and other enterprise tools that improve the flow of data.”

Living HHS Open Data Plan

HHS's Chief Data Officer published Version 1.0, the department's roadmap for open, evidence-based data practices.

HealthData.gov

Refreshed as the public front door to HHS datasets, built for transparency and innovation.

HHS Metadata Standard

Version 1.0 (July 2025): the authoritative framework for how HHS datasets describe themselves.

HHS Data Inventory

Version 1.0: a public catalog of HHS data assets, required under the Foundations for Evidence-Based Policymaking Act of 2018.

Data Maturity

A model for assessing HHS divisions' data management capability against a common bar.

Data Skills

Workforce development so staff across HHS can actually use what the department publishes.

Open Data Catalog

The searchable index of HHS's published datasets.

Data Governance

The Chief Data Officer's governing policies and stewardship structure behind all of the above.

The Peacetime Foundation — Privacy & Security

- 1 **HIPAA and the HITECH Act** set the federal floor: privacy, security, and breach-notification obligations for covered entities and business associates
- 2 **42 CFR Part 2** layers heightened consent requirements onto substance use disorder treatment records
- 3 Laws rarely anticipate innovation, but governance can fill gaps (e.g., AI-scale secondary use)
- 4 Floor preemption, rather than ceiling preemption: states and organizations may add protection, but never subtract from it

The Peacetime Foundation — Interoperability & Standards

THE RULE

The 21st Century Cures Act Information

Blocking Rule presumes access, exchange, and use of electronic health information unless a specific exception applies

USCDI/+ defines the common data elements; TEFCA connects networks of networks — nearly 500 million records exchanged nationwide as of early 2026

B.WELL IN PRACTICE

b.well's FHIR-based platform connects 1.8 million+ provider and 300+ payer sources, has demonstrated individual patient access via TEFCA with CommonWell Health Alliance, and has pledged to be a CMS-Aligned Network under the CMS Interoperability Framework

Standards adopted in peacetime are what make real-time exchange possible in an emergency

Jurisdictional Variation — State Law Over the Federal Floor

1

States may exceed HIPAA, never undercut it — California's Confidentiality of Medical Information Act and Texas's HB 300 both add narrower consent defaults, faster patient-access timelines, and broader covered-entity definitions

2

Public health reporting statutes vary by state: what's reportable, to whom, and how fast

3

The result is a **50-state patchwork** that has to be mapped before a crisis reaches multiple jurisdictions

50

State Prescription Drug Monitoring Programs, each with data rules that are state-bounded by design

When Peacetime Rules Meet Emergencies



Stafford Act / National Emergencies Act

the President's disaster or emergency declaration



Public Health Service Act §319

the HHS Secretary's public health emergency declaration



Social Security Act §1135 waivers

narrow, time-limited relief from select HIPAA Privacy Rule provisions — never a full suspension of the rule



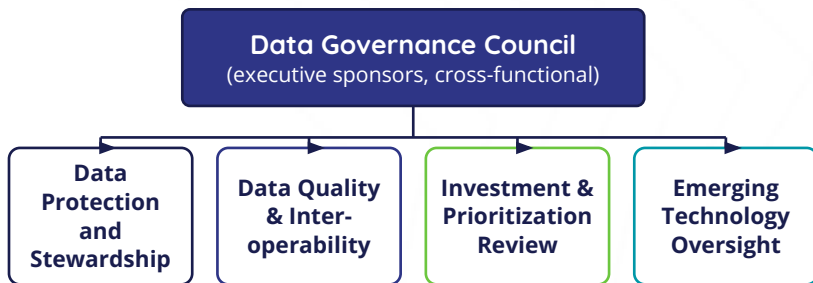
PREP Act

liability protections that can extend to the tools used to share countermeasure and response data

These are switches, not new governance — they only work if peacetime data governance already knows how to flip them

What Resilient Health Data Governance Looks Like

Operating Model



Escalation path for novel or unusual issues.

Issue & Investment Adjudication Flow



Governance Tested by Crisis

Case studies in what peacetime rules got right — and where they fell short



Case Study — Syndromic Surveillance Data

THE GAP

The National Notifiable Diseases Surveillance System ran on architecture built in the late 1980s and 1990s, with no unique national patient identifier and inconsistent state-to-CDC data vocabularies

Result: incomplete race and ethnicity data early in the pandemic, and delayed situational awareness for decision-makers

THE BRIGHT SPOT

CDC's cloud-based BioSense platform and National Syndromic Surveillance Program gave near-real-time emergency-department signals, and CDC's AI Accelerator now triages roughly 8,000 outbreak-related articles a day

Having worked inside federal public health data systems, I've seen firsthand how far standards and identifiers built in peacetime carry an emergency response

Case Study — Contact-Tracing Through Patient-Facing Apps

- 1 No federal statute governed app-based exposure data in 2020, so states improvised in real time
- 2 **Apps built on Apple and Google's Bluetooth Exposure Notification framework** were markedly more protective than GPS-based state apps
- 3 A handful of states later restricted sharing with police and immigration enforcement; most never did
- 4 **Lesson:** without a peacetime governance framework for novel data types, protections become a 50-state experiment conducted during the emergency itself

Case Study — Disaster Response & Continuity of Care



Hurricane Katrina (2005)

HHS waived select Privacy Rule provisions; KatrinaHealth.org used retail-pharmacy records to reconstruct medication histories for more than 800,000 evacuees across 150 ZIP codes, and VA's electronic health records let 200+ sites nationwide access patient data



Hurricane Maria & Superstorm Sandy

Power outages and cross-system compatibility errors limited access even where records existed electronically



Lesson

Pre-existing interoperable records plus a rehearsed legal pathway — 1135 waivers, HHS guidance — determined whether care continued without interruption

Case Study — Controlled-Substance Data Across State Lines

THE PATCHWORK

The opioid crisis was declared a public health emergency in 2017; every state runs a Prescription Drug Monitoring Program, but each is state-bounded by design

PMP InterConnect, governed by the National Association of Boards of Pharmacy, now links 40+ state PDMPs — narrowing the gap that let patients cross state lines to evade monitoring

THE TENSION & LESSON

Persistent tension: clinical use versus law-enforcement use of the same governed data; only Hawaii currently permits interstate PDMP data for research

Lesson: interoperability without a resolved governance question — who else gets to use this data, and for what — still limits its public health value



Building Data Governance That Holds

What government, organizations, and the public each need long-term



Assistant

I found a pulmonologist 4.2 miles away with the earliest opening Thursday at 10:30 AM. This visit is covered under your plan.

Would you like me to book it?

Yes, book it.



Targeted Recommendations — Before the Next Emergency

FEDERAL

Federal Agencies (HHS, CDC, ASPR, ONC)

Build identifier and vocabulary modernization as standing infrastructure

Publish the expectations in concrete, reusable terms for: data use, access, release, transfer; interoperability programs; contract and EUAs; patient data rights

STATE & LOCAL

State & Local Health Departments

Adopt USCDI/TEFCA-aligned reporting in peacetime so emergency data flows don't wait on new authorities

Negotiate interstate data-sharing agreements — leveraging the federal model — before, not during, a multi-jurisdictional event

INDUSTRY

Health Systems, Platforms & Industry

Convene multidisciplinary governance council models before being tested in crisis

Treat CMS-Aligned Network/TEFCA participation as the interoperability floor for patient/public access

Establish AI oversight as a standing enterprise function

PUBLIC

Public & Patient Leaders

Engage with decision-makers

Create plain-language, before-the-fact notice of what's collected, shared, and why

Champion patient data rights as a governance requirement, not an optional feature

A Call to Action for This Forum

The Forum on Medical and Public Health Preparedness for Disasters and Emergencies is positioned to close these gaps before, during, and after the next event:

- 1 Commission a continually updated cross-jurisdictional mapping of legal “switches” (1135 waivers, PREP Act, §319, state law) so every sector represented here knows its own authorities in advance
- 2 Recommend sustained federal funding for surveillance-system and identifier modernization as critical infrastructure, alongside physical data and response infrastructure
- 3 Extend the interstate data-sharing model proven by federal and state public health to broader health system and situational-awareness data
- 4 Endorse standards for patient-facing situational-awareness tools so empowered individuals can strengthen, rather than complicate, real-time decision-making

Governance built in peacetime is what makes situational awareness possible before, during, and after a disaster.

Key Takeaways

- 1 Build the multidisciplinary governance function before you need it — not while an emergency is unfolding
- 2 Map your legal switches — 1135 waivers, PREP Act, state law variation — in advance, across every jurisdiction you touch
- 3 Invest in data governance, including standards, identifiers, and interoperable infrastructure as core operational requirements, not IT overhead
- 4 Measure success by whether patients and health decision-makers alike understand, trust, and act on the data — before, during, and after a disaster



bwell.com • [LinkedIn](#)