



Data Governance Models

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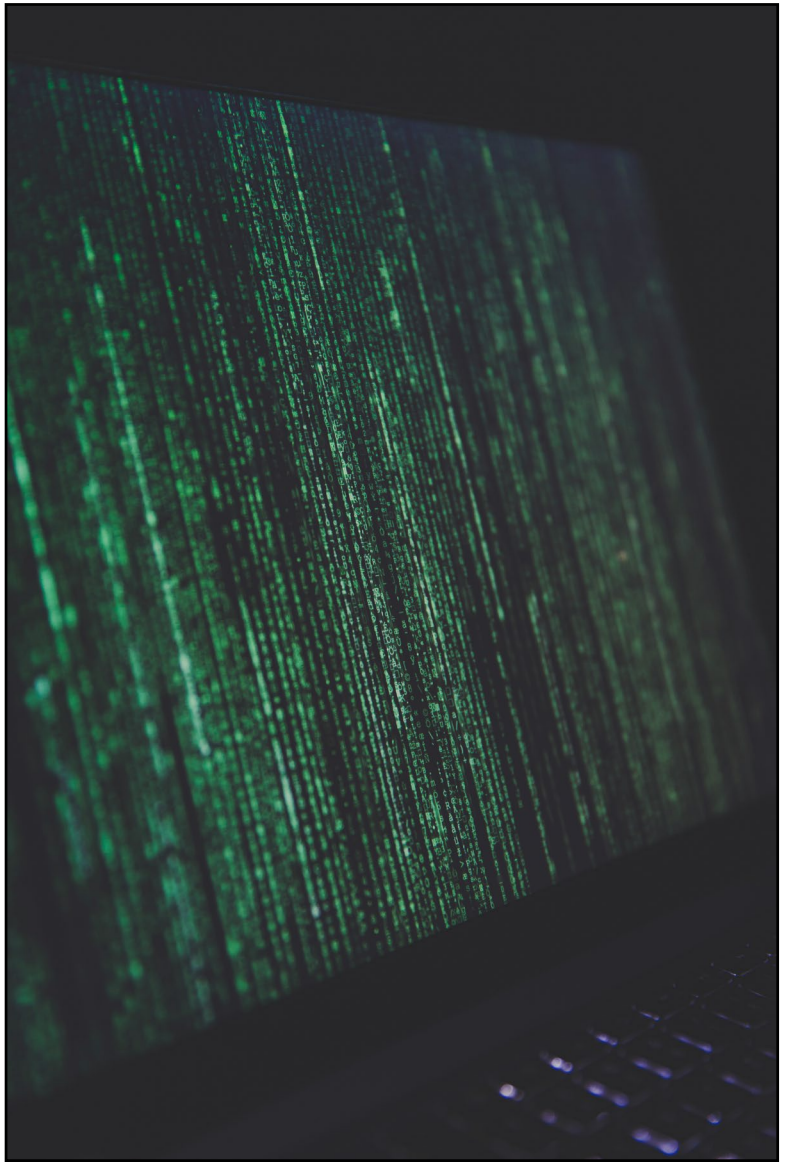
What will we cover today?

- What is data governance?
- Why data governance is vital to interoperability?
- Data governance framework
- Current models of data governance
- What is next?

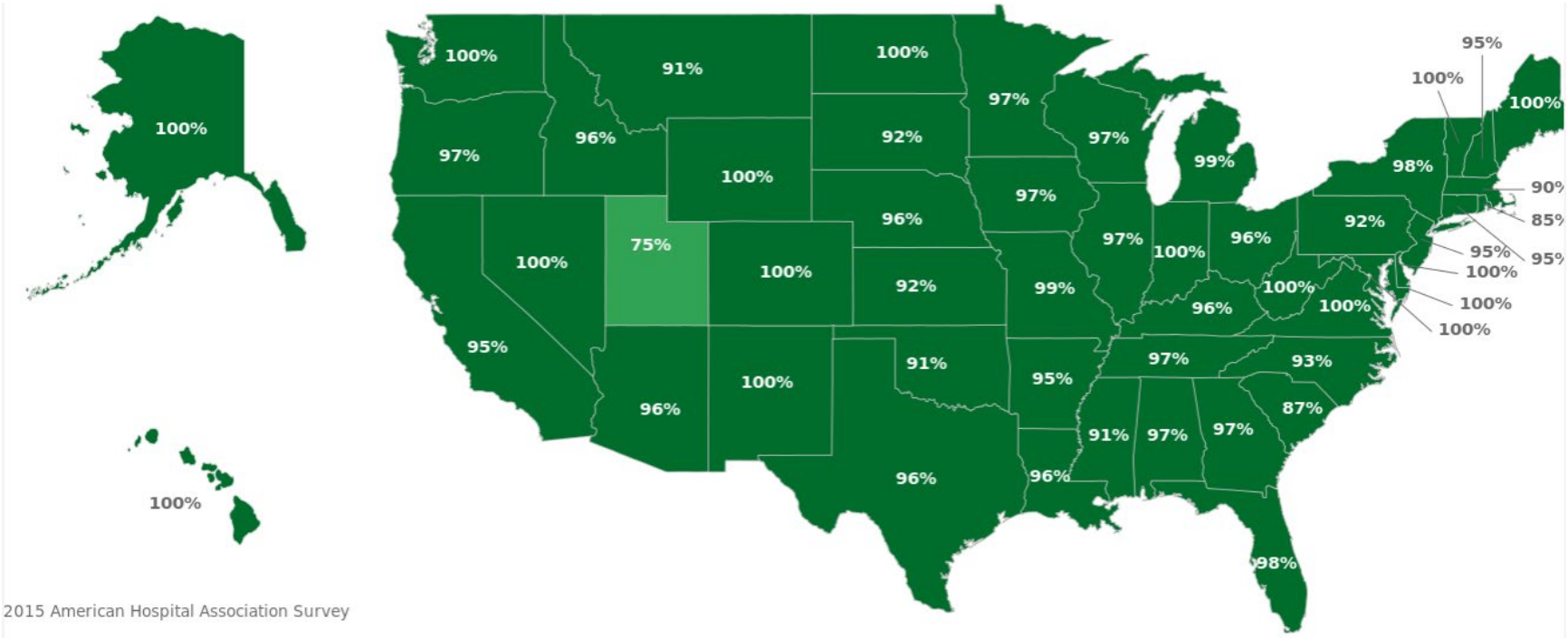


What is Data Governance?

- Identifies the “rules of engagement” for data sharing, penalties for non-compliance and oversight
- EHR technology is agnostic, it will transfer data without limits
- Users worry about when data can be requested, how is it used, data privacy and security
- Governance is a *process*, not a board

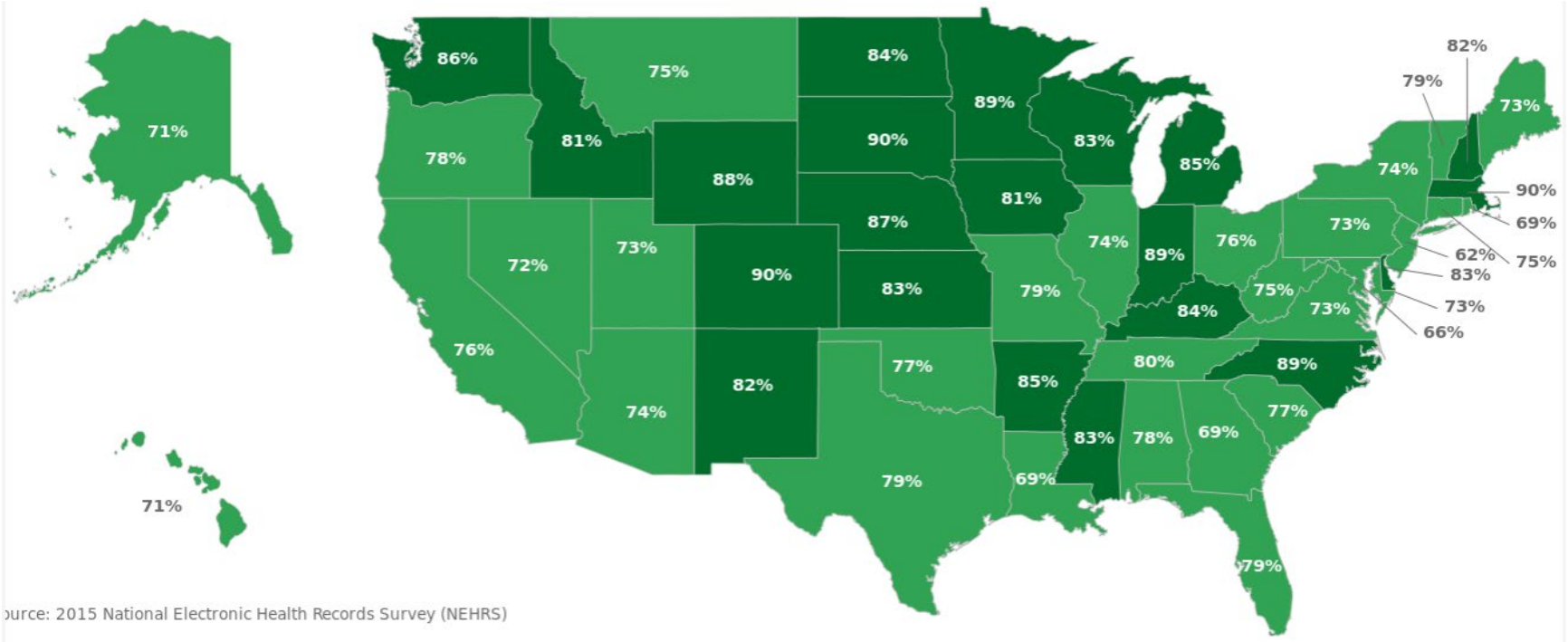
Why is data governance vital?

Percent of Hospitals That Have Adopted a Certified EHR:



Why is data governance vital?

Percent of Office-Based Physicians That Have Adopted a Certified EHR:



ource: 2015 National Electronic Health Records Survey (NEHRS)

Why is data governance vital?

- Not something new, we have always had it
- Before digital records, it was manual and point-to-point data exchange where control was easy
- Digital data changed everything!
- Without trust, data will not flow
- Absence of data can compromise delivery of care
- Increasingly difficult to operate without access to data

Data Governance Models

- No “one size fits all” data governance model
- An effective data governance framework includes both Principles and Structure
- **Principles**-what do we believe when it comes to data governance?
- **Structure-**how will we implement our Principles?
  - Data sharing agreements
  - Operating policies
  - Oversight board/committee

Governance Principles

- Where does the authority originate?
  - "top down" or "bottom up"
- Consent of the governed
- Representative governance
- Transparency
- Rules of engagement
- Enforcement

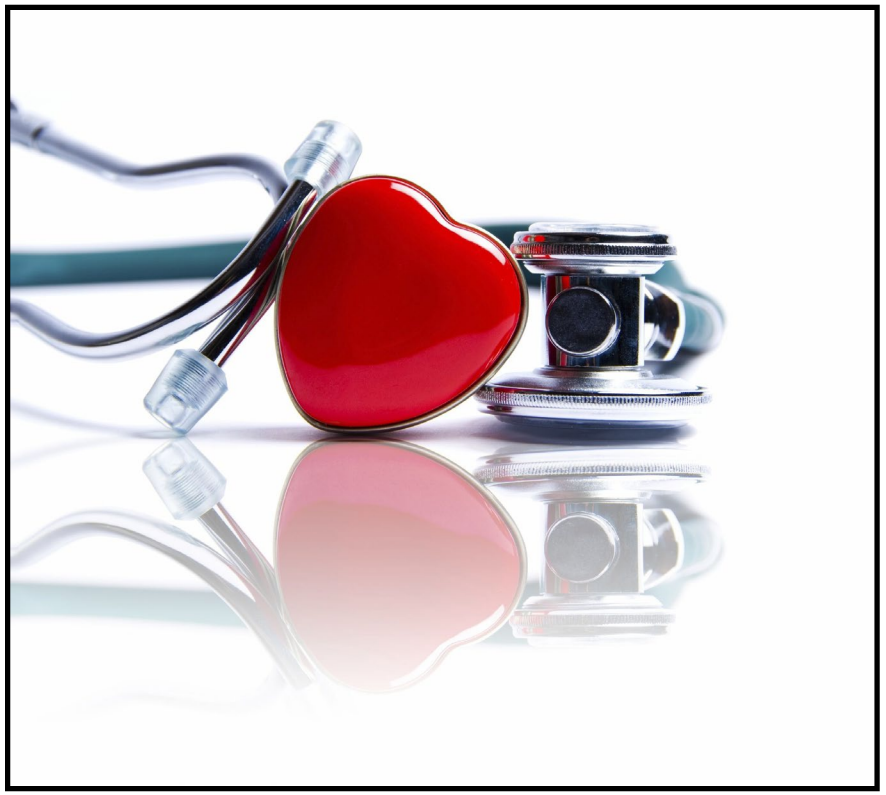
Governance Structure

- Will governance be centralized in a central body or distributed?
- Size of governance bodies?
- How is this memorialized?
  - Organizational documents
  - Trust agreement
  - Legislation or regulations
  - Other

Example 1: eHealth Exchange

- **2005**: ONC project to prove that health information can be successfully exchanged in a safe and secure manner
- **2009**: I created a first-of-its-kind multi-party data sharing agreement to support nationwide interoperability, the DURSA
- **2019**:
  - 120M patients
  - 75% of US Hospitals
  - 70,000 medical groups
  - 8300 pharmacies
  - 5200 dialysis centers
  - 60 state and regional HIEs
  - 4 major federal agencies (DoD, VA, SSA, CMS)

eHealth Exchange Governance



- **Principles**
  - Authority comes from the eHealth Exchange Participants (consent of the governed)
  - Representative
  - Transparency is more important than protecting business secrets
  - Accountable to Participants

eHealth Exchange Governance

- **Structure**
  - eHealth Exchange is not incorporated
  - Governance is memorialized in the DURSA which every Participant signs
  - Coordinating Committee is the governing body
  - Powers are listed in the DURSA

Example 2: ConnectVirginia

- Statewide Health Information Exchange
- Started as initiative of the Virginia Dept. of Health pursuant to an ONC award under the ARRA program-public health remains a key focus
- Operates several data sharing initiatives including a legislatively mandated Emergency Department Care Coordination Program that requires every hospital in Virginia to report real-time ED registrations that are matched against a central data base and alerts are fired in real time

ConnectVirginia

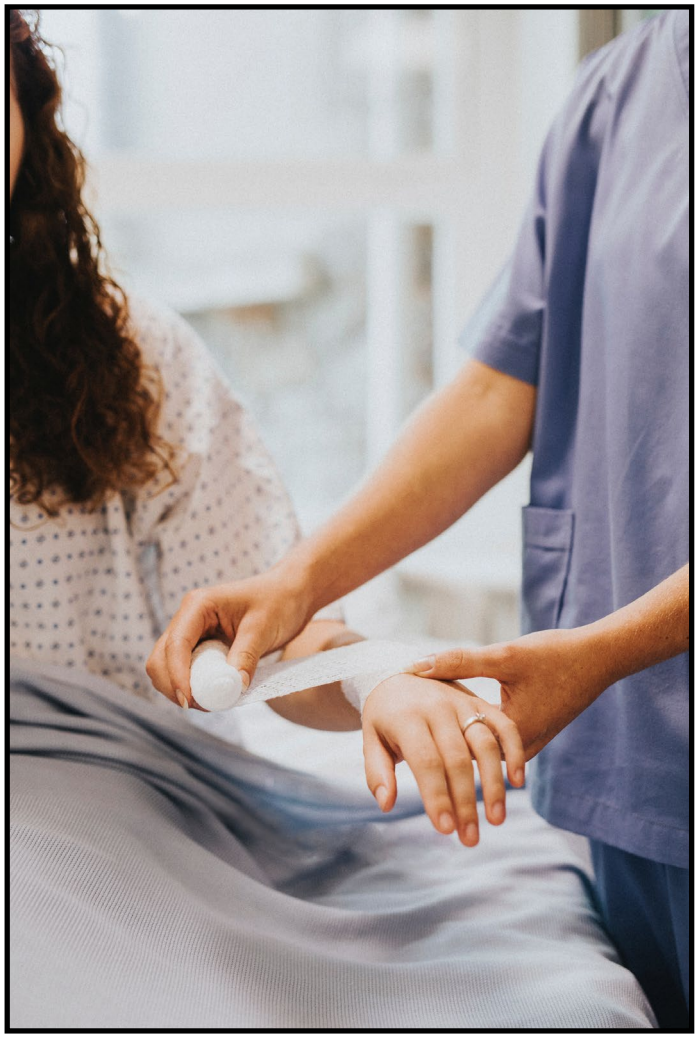
- Exchange Trust Agreement (ETA) is the trust agreement signed by all participants
- Modeled on the DURSA but customized
- Same for every Participant for transparency, same rules for everyone
- Details included in operating policies that participants have right to vote on

ConnectVirginia Governance

- 3 distinct phases which show evolution
- **Phase I: 2010-2014 *ONC contract***
  - 22-member board with all key stakeholders to support representative governance
- **Phase II: 2014-2019 *Non-profit corp.***
  - Corporate board with authority set out in bylaws
- **Phase III 2019 *Quasi-governmental***
  - Board specified in statute

Example 3: PULSE

- ONC launched initiative to help disaster health care responders have data on their patients
- Inspired by Katrina when large numbers of folks were displaced and medical information not available
- Currently being deployed in several states using eHealth Exchange as the interoperability platform



PULSE Governance

- Program is “owned” by a state or regional government as part of its EP&R
- PULSE software provided private contractor
- Data sharing supported by eHealth Exchange
- So, governance is multi-faceted
- PULSE Advisory Council is central to this

Example 4: Electronic Case Reporting

- Currently, public health disclosures are largely a paper-based process
- Utilizing established electronic connections with public health authorities, electronic case reporting (eCR) is possible

Platform Background

- APHL Informatics Messaging Service (AIMS) Platform
- Developed over a period of 10+ years using CDC and other federal grant funding
- Originally created to promote interoperability among CDC and state public health labs (PHLs)
  - Focused solely on flu reporting

AIMS Platform Today

- Now includes data transmission and messaging services between state and select local PHLs, CDC and other data exchange parties
  - Current uses include
    - Vaccine preventable disease (VPD) and rabies reporting services
    - Electronic laboratory reporting services among CDC, PHLs and commercial labs
    - Electronic vital event exchange
    - Immunization data state-to-state exchange
    - Technical support services

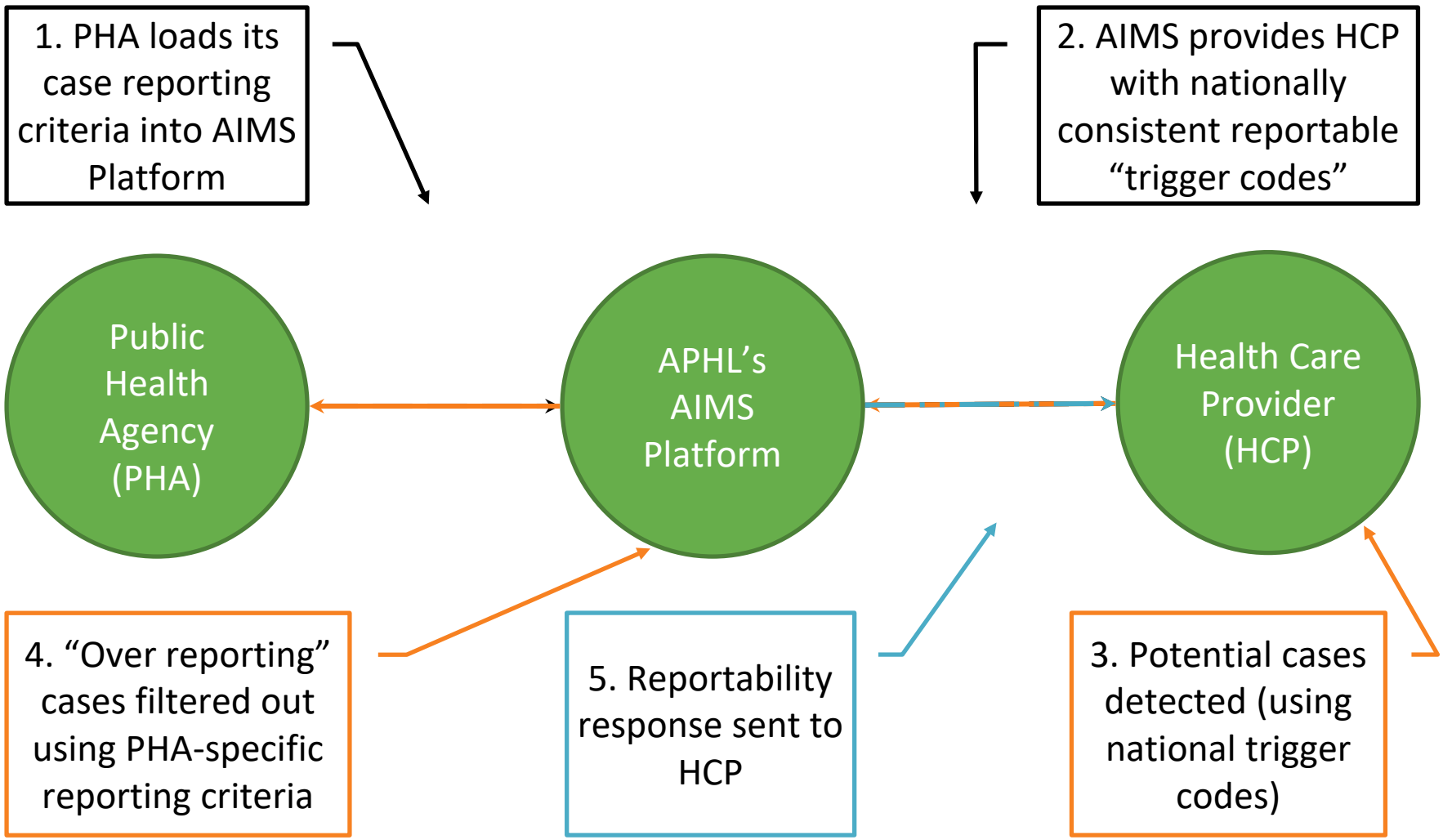
New Services

- Additional projects are under development or in pilot test phases, including
  - Electronic Case Reporting (eCR) services (pilot test sites in full production)
  - Immunization reporting services (provider to state immunization authorities)
  - Electronic test ordering and results (providers to PHLs)

eCR Overview

- Utilizes a national set of reportable trigger codes
  - A condition that is reportable in any one jurisdiction is reportable under the national set
    - For example, the national set would include
      - Colorado tick fever (reportable in some mountain states)
      - Glycohemoglobin A1c results (reportable in NYC)
- Allows for transmission of electronic initial case reports (eICRs)

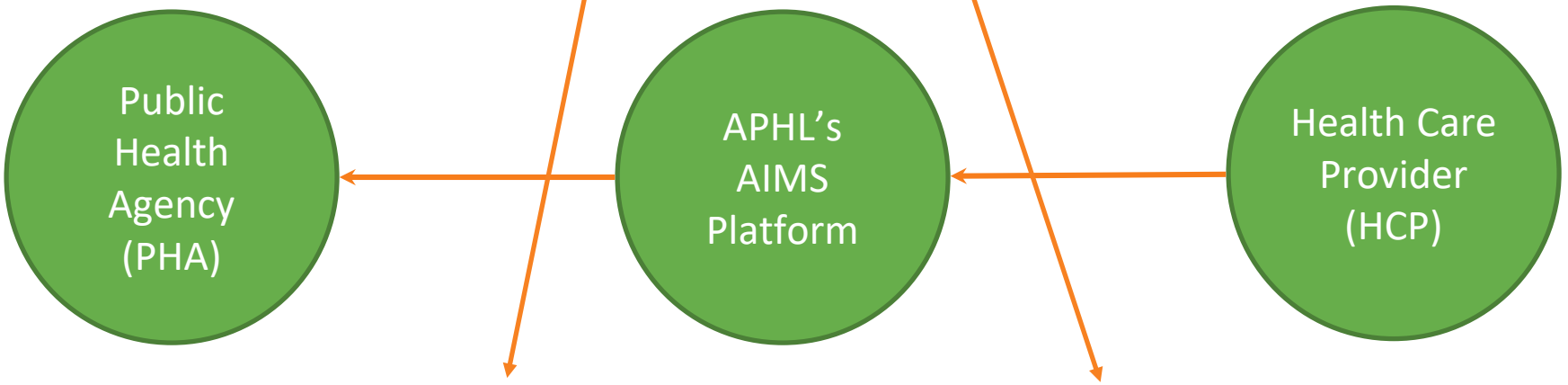
eCR Structure



Pilot Phase Data Governance

All data transmitted to PHAs allowed under HIPAA's public health exemption
45 CFR 164.514(d)(3)(i)

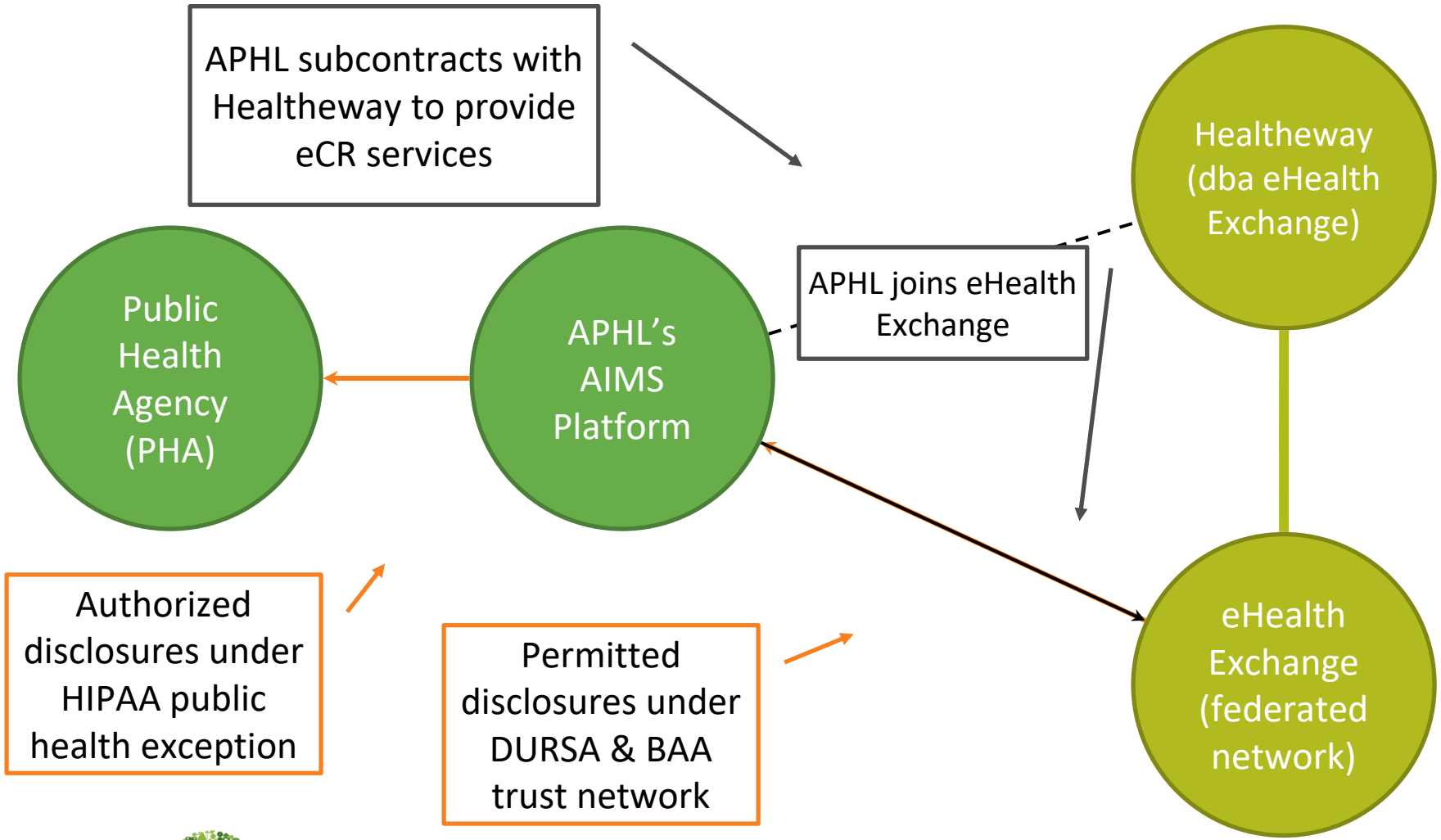
Participation Agreement and BAA with HCP needed to cover "over reporting" due to use of national trigger codes



Pilot Structure Pros & Cons

- Pros
  - Only workable option given current technology
  - Utilized familiar documentation (BAA, etc.) and framework
- Cons
  - Required substantial investment of time to review and negotiate APHL-HCP documentation
  - Required time and material investment to establish bi-directional HCP-APHL transmission

Scaling Beyond the Pilot Phase



From Pilot to National Deployment

- Utilizing the established trust network allows for an easily scalable, national deployment of eCR services
- Eliminates the need for negotiation of eCR specific BAAs and related agreements
- Allows HCPs to utilize existing connections with the trust network

Example 4: TEFCA

- Trusted Exchange Framework and Common Agreement
- Established by 21st Century Cures Act
- “single on-ramp” nationwide for interoperability
- ONC selected The Sequoia Project to serve as the Recognized Coordinating Entity
- RCE works with ONC to develop the Common Agreement over next year

What is next?

- Past the tipping point, data sharing is mandatory
- Information Blocking rule will break down data silos
- Effective data governance is essential for a learning healthcare system
- Public health key part of the ecosystem
- Your clients will want to become part of data sharing networks and governance is vital