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Data Sharing to Improve Community Health

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Data Governance Models

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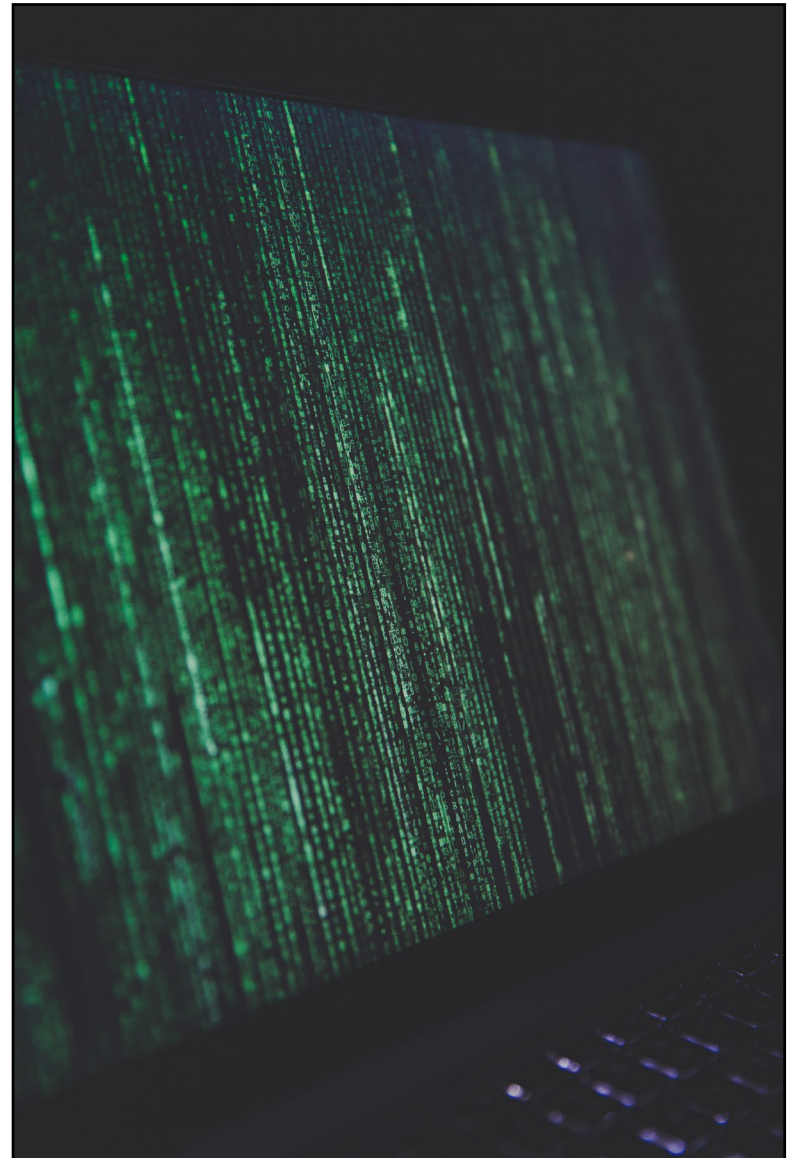
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What will we cover today?

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



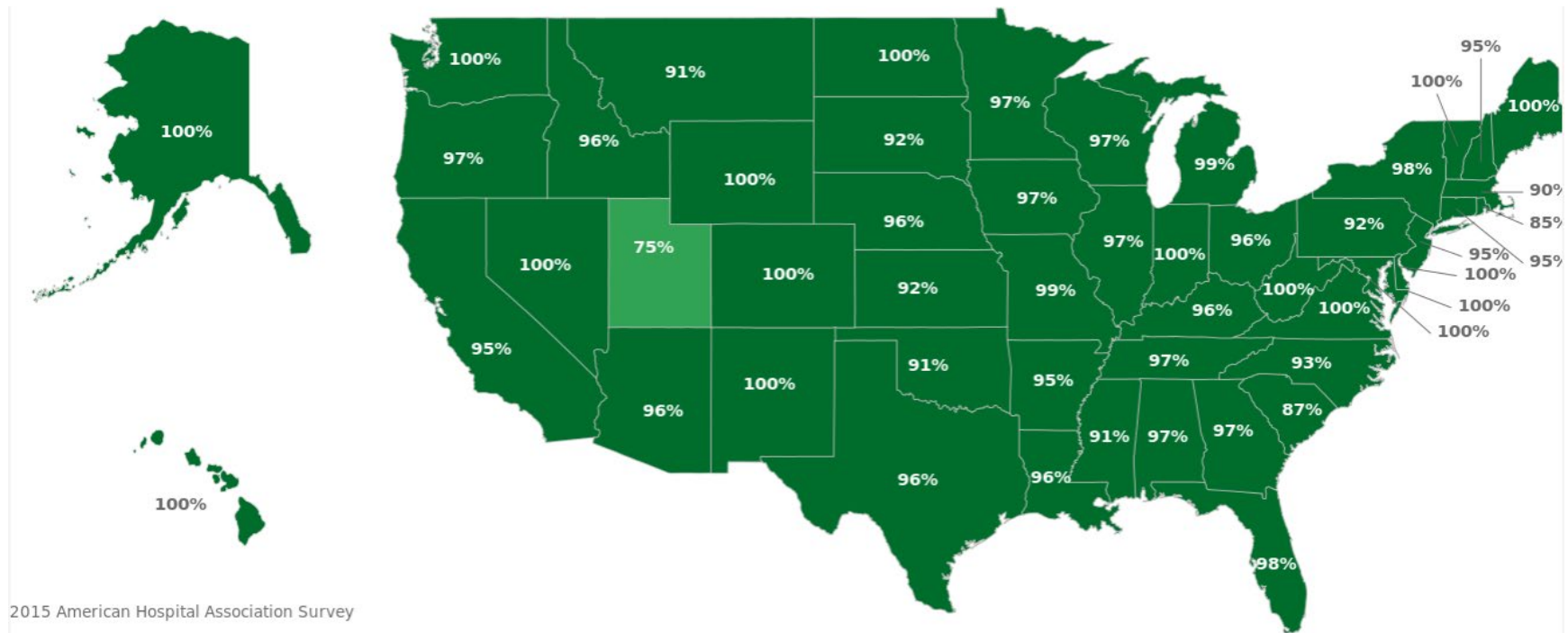
What is Data Governance?

- 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:

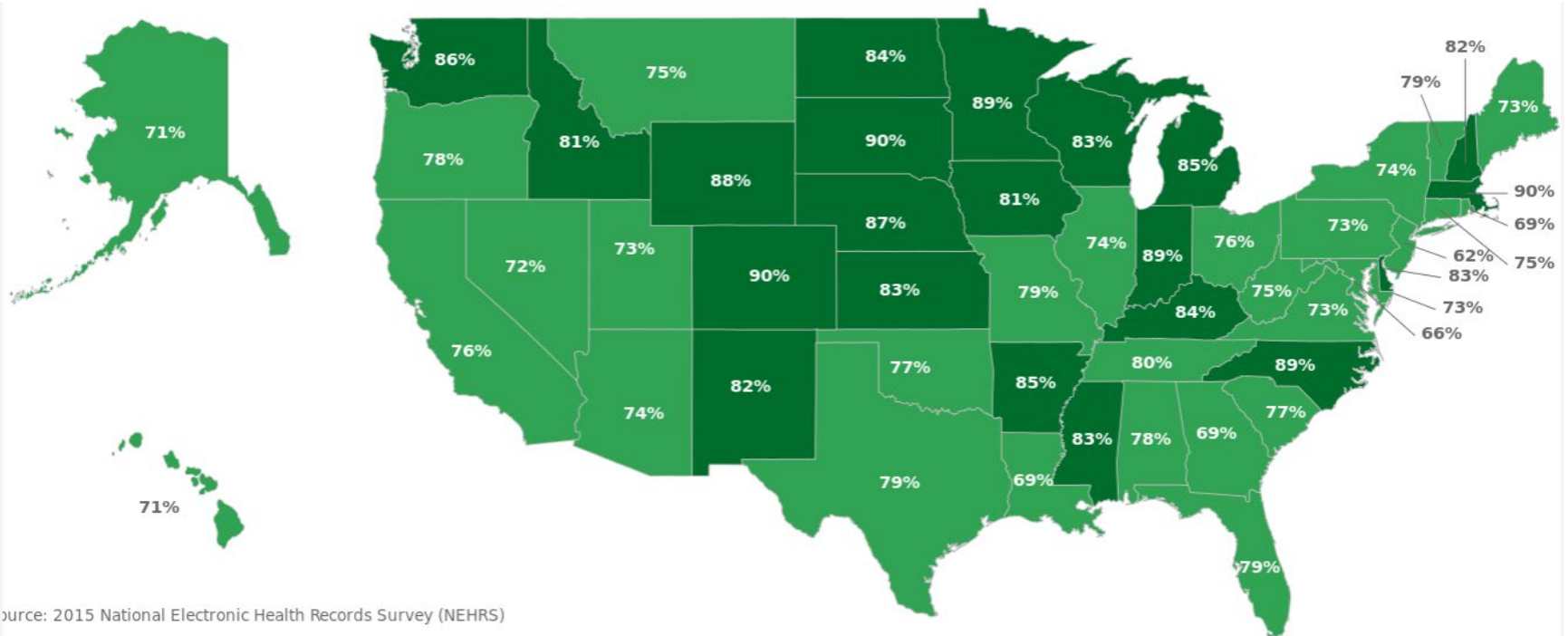


2015 American Hospital Association Survey



Why is data governance vital?

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



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)

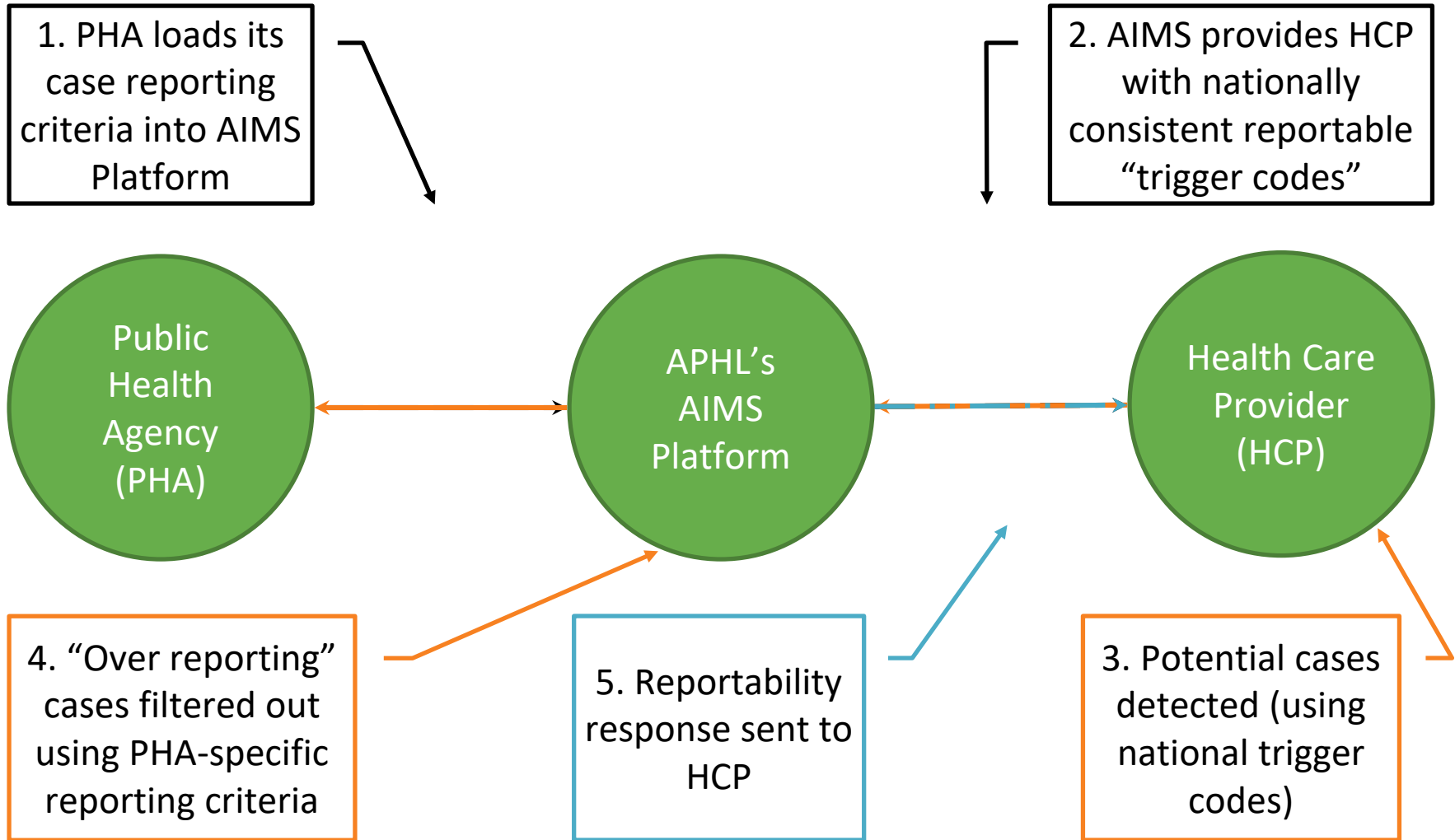


eCR Overview

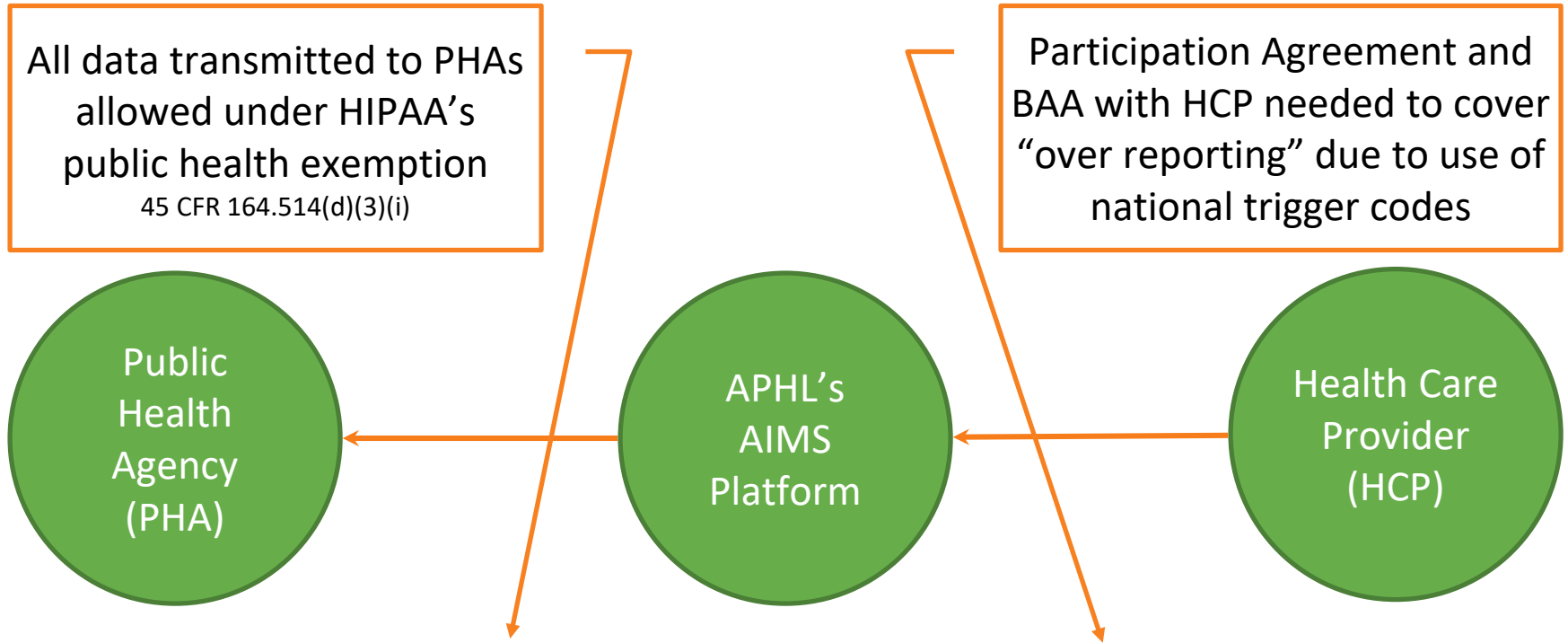
- Utilizes a national set of reportable trigger codes
 - A condition that is reportable in any one jurisdiction is reportable under the national set
 - For example, the national set would include
 - Colorado tick fever (reportable in some mountain states)
 - Glycohemoglobin A1c results (reportable in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



eCR Structure



Pilot Phase Data Governance

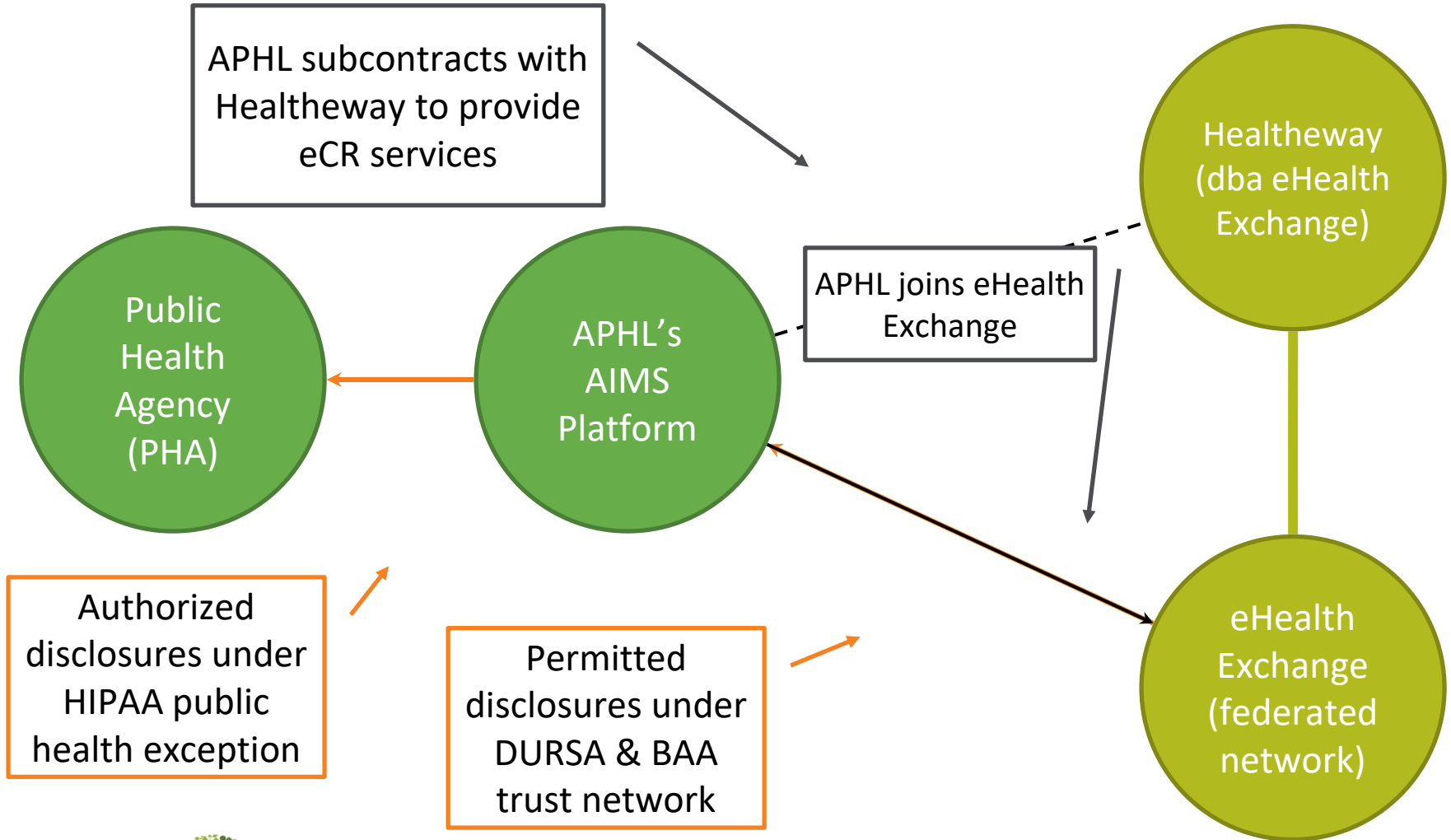


Pilot Structure Pros & Cons

- 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

