ENABLING TOOLS AND TECHNOLOGIES TO SUPPORT DELIVERY OF HIGH VALUE, COORDINATED HEALTH CARE: EVENT NOTIFICATION SYSTEMS

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INTRODUCTION

Health information exchanges (HIEs) hold great promise as a way for providers and patients to exchange information about patients' preferences, use of the health care system, and clinical results and thus to facilitate safer, more effective, and more efficient care delivery. In addition, universal access to an HIE may enable collaboration among all providers and thus enhance market functioning, relative to a setting where affiliated providers exchange information easily and unaffiliated providers do not.

In the summer of 2015, the Massachusetts Executive Office of Health and Human Services (EOHHS) and Mass-Health (the state's Medicaid program), in coordination with the Massachusetts eHealth Institute (MeHI) and the Health Policy Commission (HPC), undertook a strategic planning initiative to re-evaluate the design and focus of the state's HIE. This planning effort included a scan of state-based health information exchanges.

RESEARCH OBJECTIVES

- Document progress and best practices among state HIEs regarding five key use cases:
  1. Event notification
  2. Continuity of care documents and discharge summaries
  3. Advance directives
  4. Consent management
  5. Centralized patient portals
- Also, gather information about supporting infrastructure, including consent policies

STUDY DESIGN

Mode: Semi-structured interviews with key officials in each eight states.

Interview topics: Key stakeholders in the strategic planning process identified five key use cases for the Mass HIway and the multi-state scan:

- **Event notification systems or Admit, Discharge, Transfer alerts** provide a basic level of information exchange that increases efficiency in the health care system, while improving health outcomes for patients. ENSs alert providers and health plans when a patient is admitted, discharged, or transferred in a clinical setting and are relatively simple from a technology perspective.

- **Continuity of care documents (CCDs) and discharge summaries** represent richer exchange of patient summary information and require more advanced exchange standards.

- **Advance directives** are legal document that allow individuals to articulate their preferences for care in the event of serious illness and at the end of life.

- **Consent management** is a function whereby patients can express and update their preferences concerning which providers may access their personal health information.

- **Centralized patient portals** allow patients to have secure and easy access to a centralized portal that collects clinical and other data contributed by providers/facilities.

The interviews also touched upon each HIE's governance structure, technical architecture, performance on target metrics (e.g. production transactions, system downtime, etc.), and consent policies.

Selection of states: States were selected based on their level of progress in the identified use cases. In particular, the study prioritized states with a well-functioning ENS.
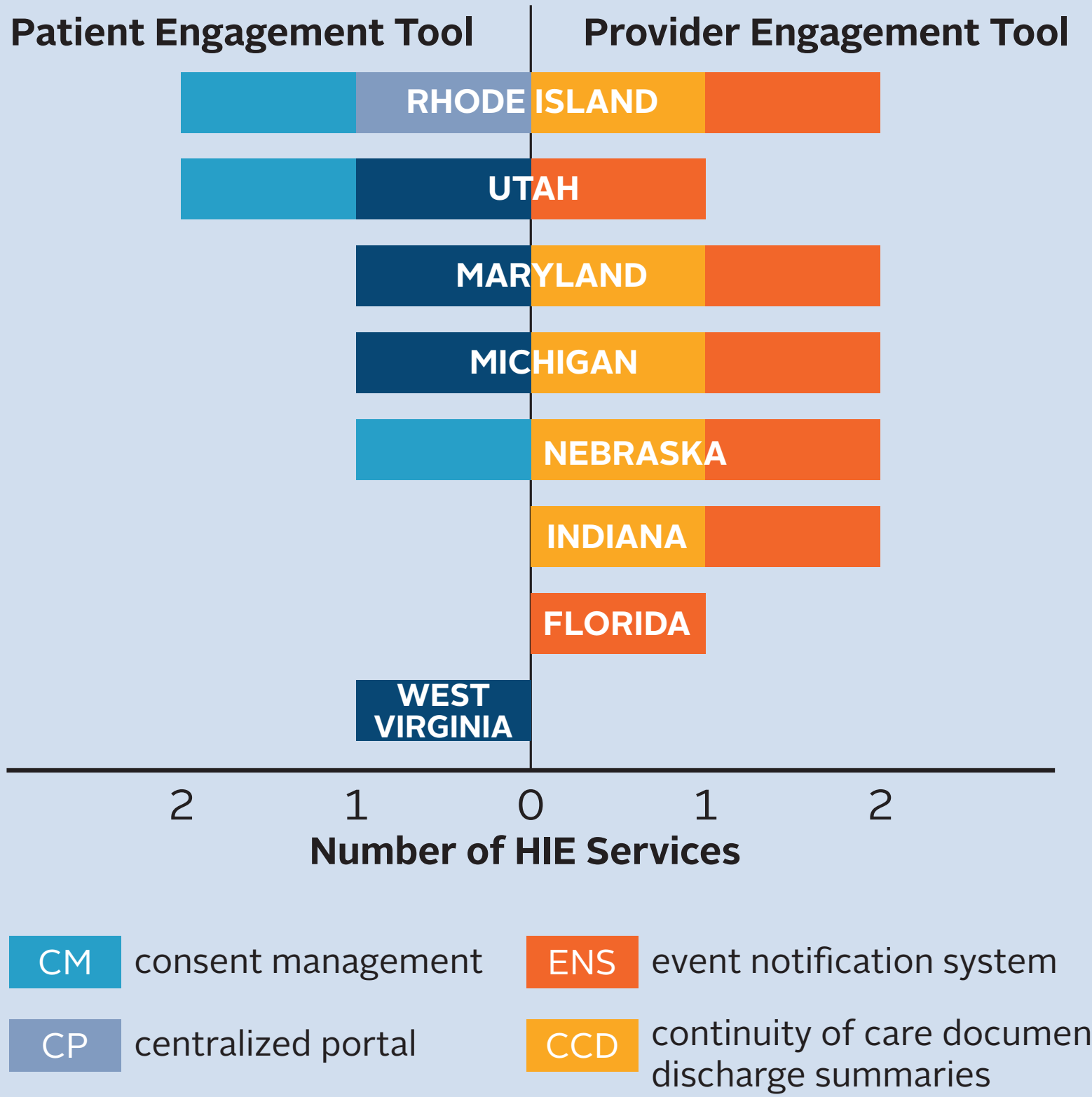
Time period: The interviews were conducted between July 21 and August, 25, 2015.

RESULTS

FIVE KEY USE CASES

Of the eight states surveyed, seven used an ENS and five used CCDs or discharge summaries; tools oriented towards providers (**Exhibit A**). Four of the eight states used some form of an electronic advance directive repository, one state offered a patient portal, and three states offered some form of consent management; tools oriented towards patients.

EXHIBIT A: HIE Use Cases

Patient Engagement Tool — Provider Engagement Tool

States listed: RHODE ISLAND, UTAH, MARYLAND, MICHIGAN, NEBRASKA, INDIANA, FLORIDA, WEST VIRGINIA

Number of HIE Services

- CM — consent management
- CP — centralized portal
- AD — advance directive
- ENS — event notification system
- CCD — continuity of care document/discharge summaries

(As of August 2015)

State officials offered the following observations and best practices relative to each use case:

ENS
- Respondents in seven states generally recommended that other states adopt ENS as one of their first HIE services, in part because it motivates providers to join the HIE.
- The majority recommended pursuing a commercial product to expedite time to market and minimize upkeep costs.
- All states observed a need to define key privacy, security, and legal parameters prior to acquiring ENS technology.
- A critical early implementation step was to determine initial data elements for ENS/ADT feeds. Many states noted that providers (particularly ACOs) should contribute to defining data elements. Many states described beginning with a limited set and expanding over time.
- States reported costs of approximately $1.1M annually.

Continuity of Care Documents and Discharge Summaries
- Respondents in four states reported that CCDs and discharge summaries currently lack consensus data elements and workflow but are high-value services where available.

Advance Directives (ADs)
- Respondents in four states reported that participation were low as a result of limited provider and consumer awareness of the available tool. In general, states had added ADs recently and were still identifying best practices.
- Different states took different approaches to consent and to hosting. Three states worked with outside organizations, while one used their State Innovation Model grant to create and host their own database. Hosted electronic forms varied among states and included MOLST, POLST, and other formats.

Consent Management and Centralized Patient Portals
- Three states had some form of online consent management and limited patient portal activity. One focused exclusively on families of children with special needs.
- While such services may be of value, states find it challenging to identify a sustainable funding mechanism. In addition, it is often a service that health plans are willing and able to provide.

- Commercial HIE vendors offer patient portal products, with consent management among their features; however, most state HIEs with patient portals are in early phases and have not adopted this capability ,and it has not been well tested.
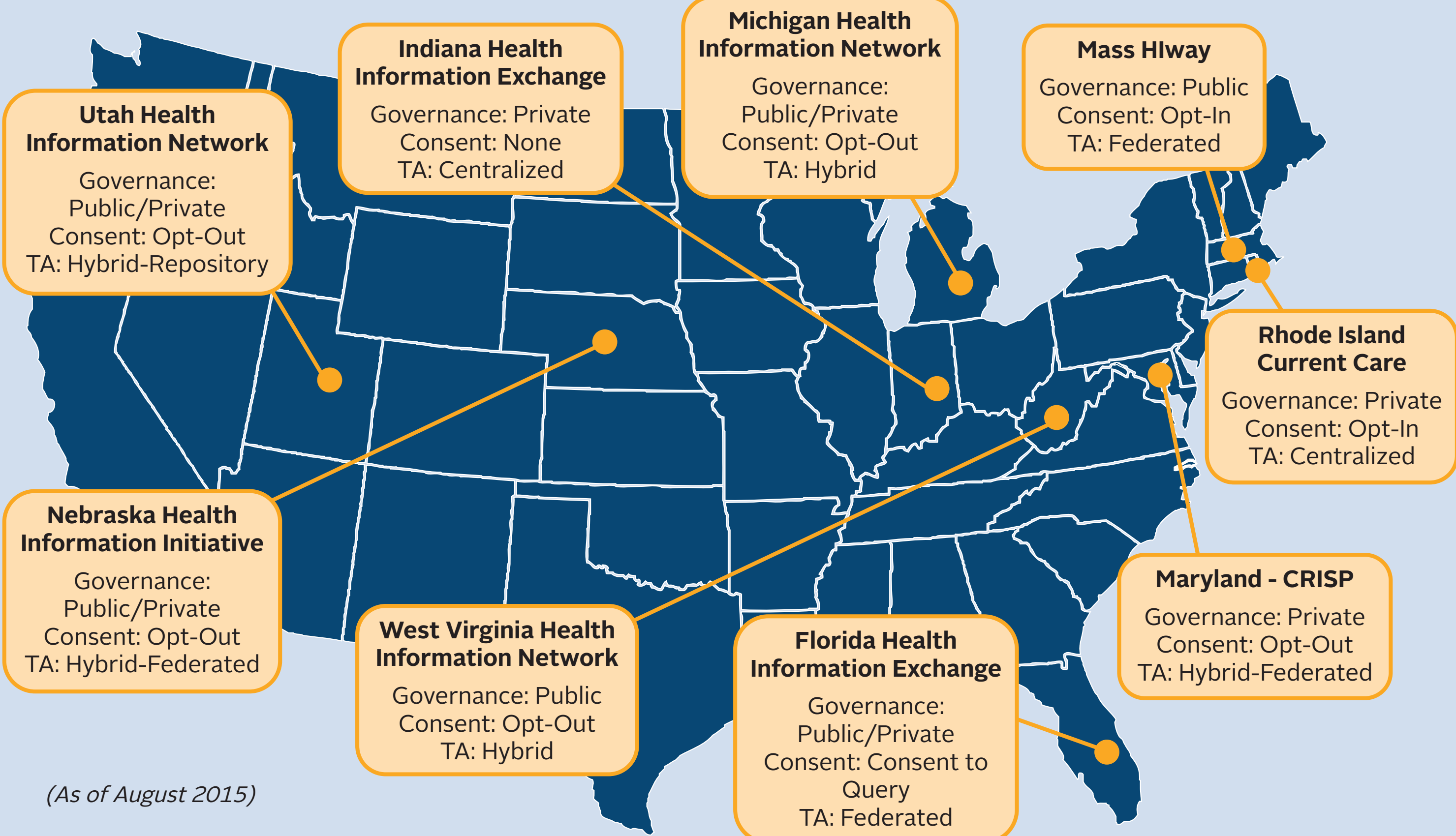
GOVERNANCE, CONSENT, AND TECHNICAL ARCHITECTURE

States varied in their approaches to governance, consent, and technical architecture (**Exhibit B**).

Of the eight states surveyed, five used opt-out consent, one used consent-to-query, one used opt-in with three levels of consent of which the patient can choose, and one used no consent for the HIE, taking the view that consent to treat encompasses consent to exchange the information necessary for treatment.

In states with opt-out consent, few patients opt out of the HIE. In one such state, the HIE reported that no requests have been made in the nearly four years of HIE operations. In another, even after an extensive consumer education campaign about patients' right to opt-out, 3% of patients declined to participate in the HIE.

EXHIBIT B

Utah Health Information Network
Governance: Public/Private
Consent: Opt-Out
TA: Hybrid-Repository

Indiana Health Information Exchange
Governance: Private
Consent: None
TA: Centralized

Michigan Health Information Network
Governance: Public/Private
Consent: Opt-Out
TA: Hybrid

Mass HIway
Governance: Public
Consent: Opt-In
TA: Federated

Rhode Island Current Care
Governance: Private
Consent: Opt-In
TA: Centralized

Nebraska Health Information Initiative
Governance: Public/Private
Consent: Opt-Out
TA: Hybrid-Federated

West Virginia Health Information Network
Governance: Public
Consent: Opt-Out
TA: Hybrid

Florida Health Information Exchange
Governance: Public/Private
Consent: Consent to Query
TA: Federated

Maryland - CRISP
Governance: Private
Consent: Opt-Out
TA: Hybrid-Federated

(As of August 2015)

CONCLUSIONS

Respondents in eight states offered diverse perspectives on HIE development, and each state had developed its HIE in response to a unique set of circumstances. However, taken together the eight interviews suggested the following best practices:

1. Providers' active participation is critical to a successful HIE.
2. Patient engagement is required to earn patient trust, especially in states with opt-in consent; patients' support and participation also motivates provider use of the HIE.
3. ENS can be a foundational element to increase provider participation in an HIE and can lead to an increased interest and demand for other HIE services (e.g. CCD, advance directive, etc.).
4. States can use policy tools, such as mandating HIE activities or altering consent policies, to increase provider participation in the HIE.
5. Structural and foundational elements (such as patient matching) should be considered prior to developing ENS and other HIE tools.

POLICY IMPLICATIONS

State policy-makers in Massachusetts and elsewhere may wish to consider these observations and best practices in refining plans for their HIEs.

In Massachusetts, since the conclusion of this study, new regulations have been proposed to improve and clarify patient consent policies for the Mass HIway. In addition, the HIE is researching new ways to improve patient care and care coordination through vendor-hosted and HIE-hosted tools.

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