Governance Design Group:
Recommendations and Considerations for the Health IT Advisory Council

July 19, 2018

OHS CONNECTICUT Office of Health Strategy

CONNECTICUT HEALTH INFORMATION TECHNOLOGY OFFICE

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Structure and Process

Project Structure

Executive Sponsor
Allan Hackney, Connecticut's Health Information Technology Officer (HITO)

Project Oversight
Health IT Advisory Council - Member Listing

Members
Lisa Stump, MS - Health Systems / Health IT Advisory Council
Pat Checko, DrPH - Consumers / Health IT Advisory Council
Jake Star - LTPAC / Health IT Advisory Council
Bruce Adams, JD - Office of the Lieutenant Governor
Bill Roberts, JD - Office of the Attorney General (on assignment from Shipman & Goodwin)
Commissioner Roderick Bremby – DSS Representative (supported by Polly Bentley and Joe Stanford)

Support Staff
HIT PMO
Jennifer Richmond
Sarju Shah
MJ Lamelin
Grace Capreol
Kelsey Lawlor
Dino Puia

CedarBridge Group
Michael Matthews, Lead
Chris Robinson, PM

Consulted:
Victoria Veltri, Executive Director, Office of Health Strategy

Purpose of Governance Design Group

Develop **recommendations for the Health IT Advisory Council to address:**

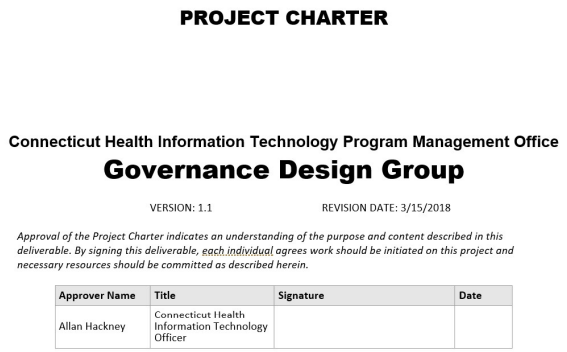
- **Relationship of Health IT Advisory Council, the State of Connecticut, the HIE entity, and the Health Information Technology Officer within the Office of Health Strategy**
- Pros and cons of establishing **a new HIE entity or designating an existing entity with recommendations**
- Baseline elements of **a trust framework and agreement**
- Table of contents for HIE **Policies and Procedures**
- **Critical success factors** in HIE governance

Goals and Objectives of Governance Design Group

- Develop **high-level requirements for the Connecticut HIE governance structure**
- Define **attributes of a "neutral and trusted entity"**
- Review **models of governance** used successfully by other state HIEs
- Review **state and national legislation and regulations** that should inform HIE governance
- **Review existing trust frameworks and trust agreements** commonly used for interoperability and HIE initiatives

Design Group Charter

- Project purpose
- Project goals and objectives
- Project scope
- Critical success factors
- Project milestones
- Project structure



PROJECT CHARTER

Connecticut Health Information Technology Program Management Office

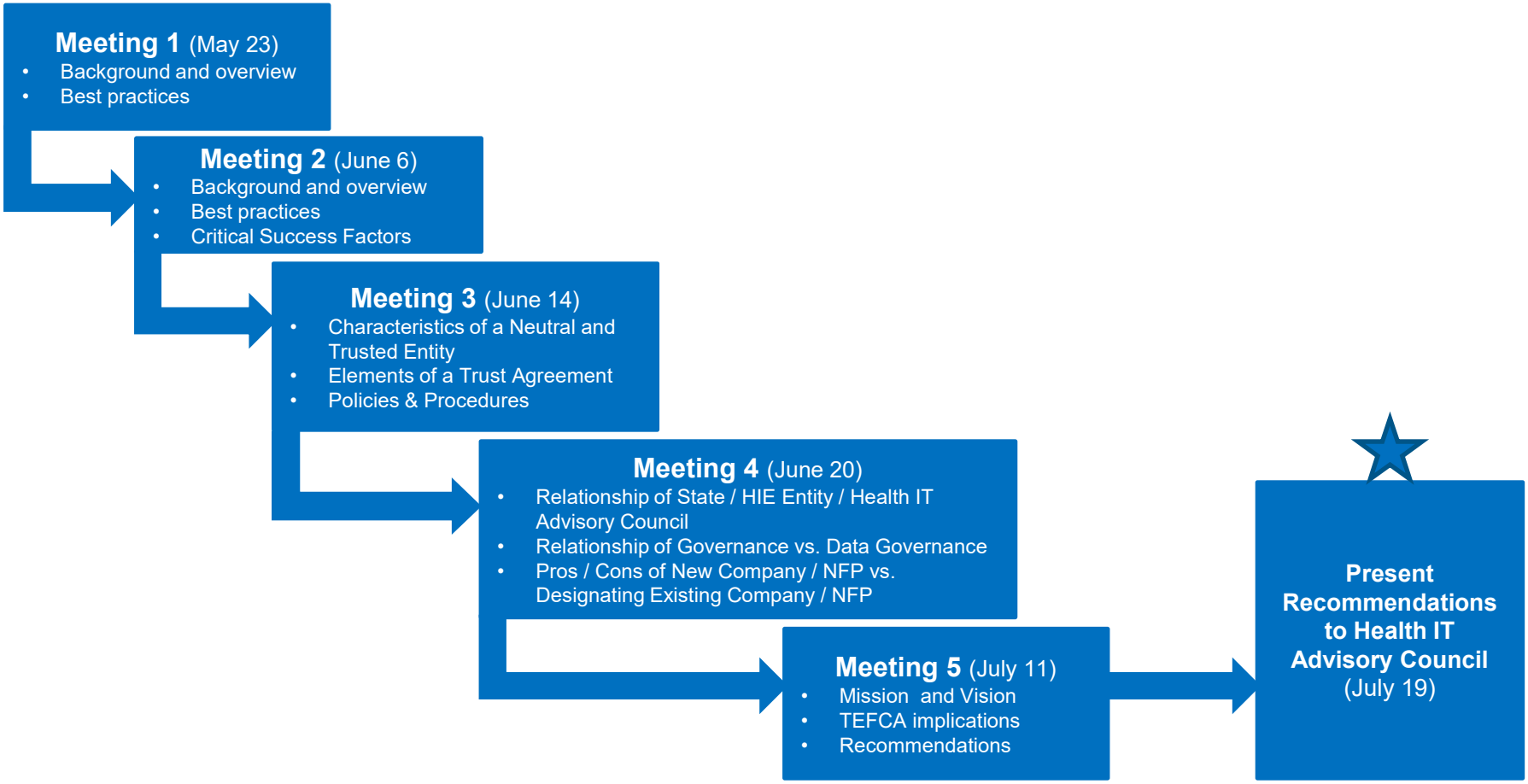
Governance Design Group

VERSION: 1.1 REVISION DATE: 3/15/2018

Approval of the Project Charter indicates an understanding of the purpose and content described in this deliverable. By signing this deliverable, each individual agrees work should be initiated on this project and necessary resources should be committed as described herein.

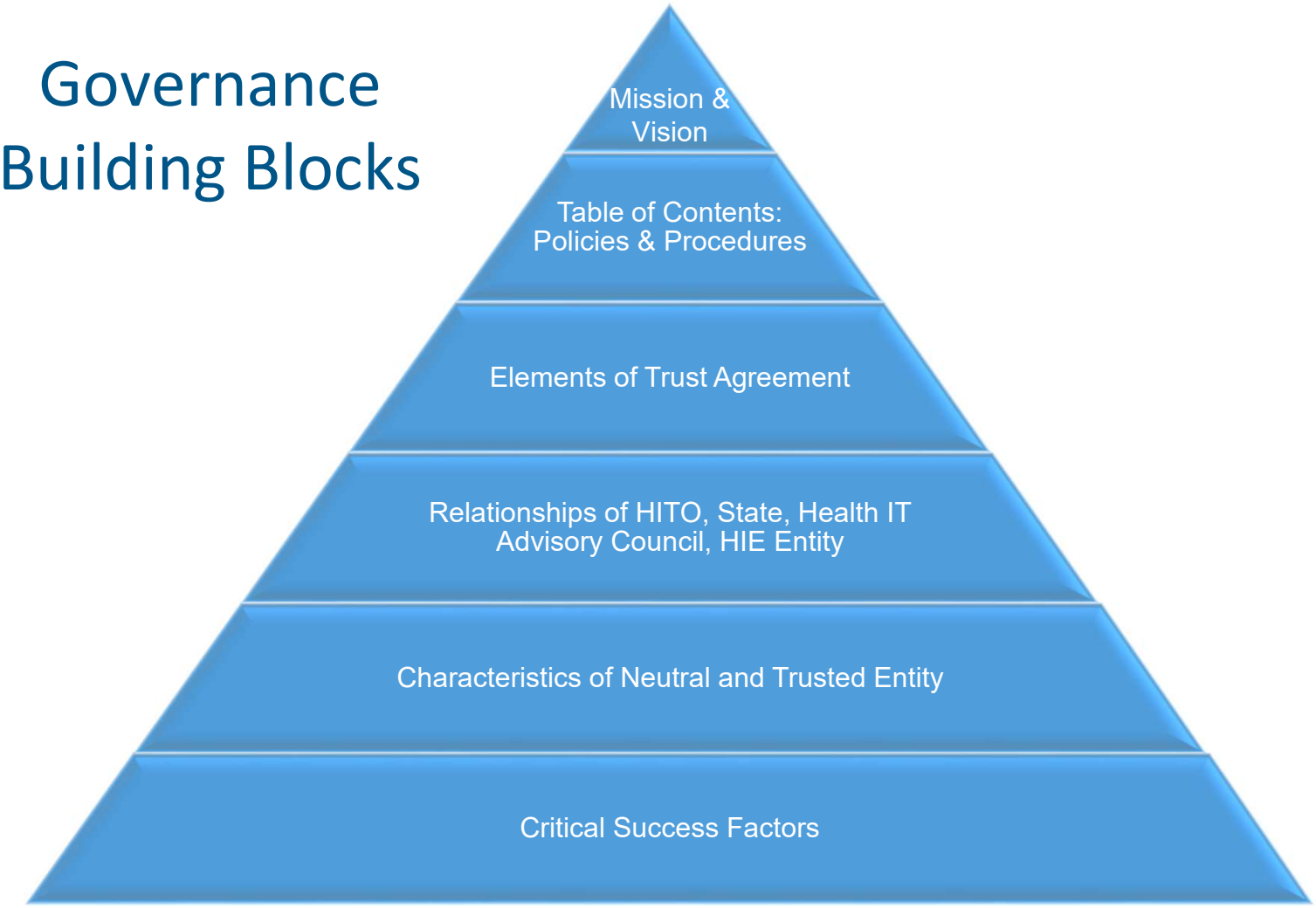
Approver Name	Title	Signature	Date
Allan Hackney	Connecticut Health Information Technology Officer		

Meeting Schedule



Governance Building Blocks and Summary of Recommendations

Governance Building Blocks



Recommendations and Guiding Principles

1. The **mission, vision and values** of the HIE entity should be informed by recommendations approved by the Health IT Advisory Council in May 2017
2. **Factors critical to the success** of the HIE entity should be identified, adopted and used to underpin governance, strategy and operations.
3. The HIE entity serving as the corporate home for HIE should be **neutral and trusted**. The entity will be owned and governed by a party or parties other than the state and may be organized as a nonprofit entity. Characteristics of a neutral and trusted entity should guide the formation and ongoing governance of the HIE entity.
4. **The relationship of the State of CT to the HIE governance** should be clear, transparent, and in alignment with CT statutes including P.A. 17-2 (as amended by P.A. 18-91).
5. A **new not-for-profit entity should be strongly considered** as the corporate home for HIE services and activities though only after a thorough review of other options (i.e., designation of an existing entity); such review should be undertaken as soon as practicable.
6. A robust data governance function is essential for ensuring best practices for handling of data related to health information exchange, analytics and corporate activities. **Data governance should be overseen by a Data Governance Council, functioning under the overall corporate governance oversight of the HIE entity**.
7. **Trust agreements** should be developed and implemented that codify "rules of the road" for data sharing and data usage, consistent with Federal and State statutes and regulations.
8. Governance practices should be supported by a **robust set of policies and procedures** that ensure fiduciary responsibilities and oversight of activities are fulfilled.
9. Governance of health information exchange and data sharing within the State of CT should **be conformant with the Trusted Exchange Framework and Common Agreement (TEFCA)** currently under development by the Office of the National Coordinator for Health Information Technology (ONC) pursuant to the 21st Century Cures Act.

Background

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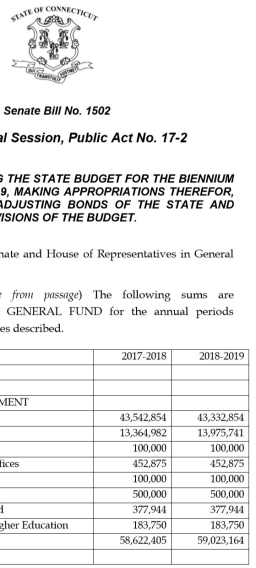
Background:

Senate Bill No. 1502

June Special Session Public Act No. 17-2 (Amended by P.A. 18-91)



Senate Bill No. 1502

June Special Session, Public Act No. 17-2

AN ACT CONCERNING THE STATE BUDGET FOR THE BIENNIUM ENDING JUNE 30, 2019, MAKING APPROPRIATIONS THEREFOR, AUTHORIZING AND ADJUSTING BONDS OF THE STATE AND IMPLEMENTING PROVISIONS OF THE BUDGET.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

Section 1. (*Effective from passage*) The following sums are appropriated from the GENERAL FUND for the annual periods indicated for the purposes described.

	2017-2018	2018-2019
LEGISLATIVE		
LEGISLATIVE MANAGEMENT		
Personal Services	43,542,854	43,332,854
Other Expenses	13,364,982	13,975,741
Equipment	100,000	100,000
Interim Salary/Caucus Offices	452,875	452,875
Redistricting	100,000	100,000
Old State House	500,000	500,000
Interstate Conference Fund	377,944	377,944
New England Board of Higher Education	183,750	183,750
AGENCY TOTAL	58,622,405	59,023,164

Public Act No. 17-2, Amended by P.A. 18-91 (1 of 7)

- HITO and Secretary of OPM may establish or incorporate an entity to implement the program
- Such entity shall, without limitation, be owned and governed, in whole or in part, by a party or parties other than the state and may be organized as a nonprofit entity.
- Any entity established or incorporated shall have its powers vested in and exercised by a board of directors. The board of directors shall be comprised of the following members who shall each serve for a term of two years. One member who shall have expertise in the following areas:
  - Advocate for consumers of health care, appointed by the Governor;
  - Clinical medical doctor, appointed by the President Pro Tempore of the Senate;
  - Hospital administration, appointed by the Speaker of the House of Representatives;
  - Corporate law or finance, appointed by the Minority Leader of the Senate;
  - Group health insurance coverage, appointed by the minority leader of the House of Representatives;
  - The Chief Information Officer, the Secretary of the Office of Policy and Management and the Health Information Technology Officer, or their designees, who shall serve as ex-officio, voting members of the board; and
  - The Health Information Technology Officer, or his or her designee, who shall serve as chairperson of the board

Relevant Provisions of 17-2, Amended by P.A. 18-91 (2 of 7)

June Special Session PA 17-2 (continued):

Sec. 128 (e) – "The entity established under subsection (c) of this section may":

- Employ a staff and fix their duties, qualifications, and compensation
- Solicit, receive, and accept aid or contributions (money, property, labor, or other things of value) from any source
- Receive and manage on behalf of the state, funding from the federal government, other public sources or private sources to cover costs associated with the planning, implementation, and administration of the HIE
- Collect and remit fees set by the HITO charged to persons or entities for access to or interaction with the HIE
- Retain outside consultants and technical experts
- Maintain an office in the state at such place or places as such entity may designate
- Procure insurance against loss in connection with such entity's property and other assets
- Sue and be sued and plead and be impleaded
- Borrow money for the purpose of obtaining working capital
- **Subject to the powers, purposes, and restrictions of sections 17b-59a, 17b-59d, 17b-59f, and 19a-755 of the general statutes, do all acts and things necessary and convenient to carry out the purposes of this section and section 164 of this act (the establishment of the Office of Health Strategy).**

Relevant Provisions of 17-2, Amended by P.A. 18-91 (3 of 7)

June Special Session PA 17-2:

Sec. 112. Section 19a-755 of the general statutes is repealed and the following is substituted in lieu thereof (Effective from passage):

a) The Lieutenant Governor shall, within existing resources, designate an individual to serve as Health Information Technology Officer. The Health Information Technology Officer shall

1. be responsible for **coordinating all state health information technology initiatives**; [and]
2. seek funding for and oversee the planning, implementation and development of policies and procedures for the **administration of the all-payer claims database program** established under section 113 of this act; and
3. establish and maintain a **consumer health information Internet web site** as described in section 114 of this act. The Health Information Technology Officer may seek private and federal funds for staffing to support such initiatives.

b) **The Health Information Technology Officer shall, in consultation with the Health Information Technology Advisory Council, maintain written procedures for implementing and administering the all-payer claims database program** established under section 113 of this act. Any such written procedures shall include (1) reporting requirements for reporting entities, as defined in section 113 of this act; and (2) requirements for providing notice to a reporting entity, as defined in section 113 of this act, of any alleged failure on the part of such reporting entity to comply with such reporting requirements.

(c) Unless expressly specified, nothing in this section or section 113 of this act and no action taken by the Health Information Technology Officer pursuant to this section or section 113 of this act shall be construed to preempt, supersede or affect the authority of the Insurance Commissioner to regulate the business of insurance in the state.

Relevant Provisions of 17-2, Amended by P.A. 18-91 (4 of 7)

June Special Session PA 17-2:

Sec. 127. Section 17b-59f of the general statutes, as amended by section 7 of public act 17-188, is repealed and the following is substituted in lieu thereof (Effective from passage):

There shall be a **State Health Information Technology Advisory Council to advise the Health Information Technology Officer**, designated in accordance with section 19a-755, in

- developing priorities and policy recommendations for advancing the state's health information technology and health information exchange efforts and goals and
- to advise the Health Information Technology Officer in the development and implementation of the state-wide health information technology plan and standards and the State-wide Health Information Exchange, established pursuant to section 17b-59d.
- The advisory council shall also advise the Health Information Technology Officer regarding the development of appropriate governance, oversight and accountability measures to ensure success in achieving the state's health information technology and exchange goals.

Relevant Provisions of 17-2, Amended by P.A. 18-91 (5 of 7)

June Special Session PA 17-2:

(d) (1) **The Health Information Technology Officer, appointed in accordance with section 19a-755, shall serve as a chairperson of the council**. The **council shall elect a second chairperson from among its members, who shall not be a state official.** The chairpersons of the council may establish subcommittees and working groups and may appoint individuals other than members of the council to serve as members of the subcommittees or working groups.

(e) (1) The council shall establish a working group to be known as the **All-Payer Claims Database Advisory Group**.

Relevant Provisions of 17-2, Amended by P.A. 18-91 (6 of 7)

1. The Health Information Technology Officer, appointed in accordance with section 19a-755, or the Health Information Technology Officer's designee;
2. The Commissioners of Social Services, Mental Health and Addiction Services, Children and Families, Correction, Public Health and Developmental Services, or the Commissioners' designees;
3. The Chief Information Officer of the state, or the Chief Information Officer's designee;
4. The chief executive officer of the Connecticut Health Insurance Exchange, or the chief executive officer's designee;
5. The director of the state innovation model initiative program management office, or the director's designee;
6. The chief information officer of The University of Connecticut Health Center, or said chief information officer's designee;
7. The Healthcare Advocate, or the Healthcare Advocate's designee;
8. The Comptroller, or the Comptroller's designee;
9. Five members appointed by the Governor, one each of whom shall be (A) a representative of a health system that includes more than one hospital, (B) a representative of the health insurance industry, (C) an expert in health information technology, (D) a health care consumer or consumer advocate, and (E) a current or former employee or trustee of a plan established pursuant to subdivision (5) of subsection (c) of 29 USC 186;
10. Three members appointed by the president pro tempore of the Senate, one each who shall be (A) a representative of a federally qualified health center, (B) a provider of behavioral health services, and (C) a representative of the Connecticut State Medical Society;
11. Three members appointed by the speaker of the House of Representatives, one each who shall be (A) a technology expert who represents a hospital system, as defined in section 19a-486i, (B) a provider of home health care services, and (C) a health care consumer or a health care consumer advocate;
12. One member appointed by the majority leader of the Senate, who shall be a representative of an independent community hospital;
13. One member appointed by the majority leader of the House of Representatives, who shall be a physician who provides services in a multispecialty group and who is not employed by a hospital;
14. One member appointed by the minority leader of the Senate, who shall be a primary care physician who provides services in a small independent practice;
15. One member appointed by the minority leader of the House of Representatives, who shall be an expert in health care analytics and quality analysis;
16. The president pro tempore of the Senate, or the president's designee;
17. The speaker of the House of Representatives, or the speaker's designee;
18. The minority leader of the Senate, or the minority leader's designee; and
19. The minority leader of the House of Representatives, or the minority leader's designee.

(c) Any member appointed or designated under subdivisions [(9)] (10) to [(18)] (19), inclusive, of subsection (b) of this section may be a member of the General Assembly.

The chairpersons of the council may appoint up to four additional members to the council, who shall serve at the pleasure of the chairpersons.

Relevant Provisions of 17-2, Amended by P.A. 18-91 (7 of 7)

June Special Session PA 17-2:

Sec. 128. (NEW) (Effective from passage) (a) **The state, acting by and through the Secretary of the Office of Policy and Management, in collaboration with the Health Information Technology Officer** designated under section 19a-755 of the general statutes, and the Lieutenant Governor, **shall establish a program to expedite the development of the State-wide Health Information Exchange**, established under section 17b-59d of the general statutes, to assist the state, health care providers, insurance carriers, physicians and all stakeholders in empowering consumers to make effective health care decisions, promote patient-centered care, improve the quality, safety and value of health care, reduce waste and duplication of services, support clinical decision-making, keep confidential health information secure and make progress toward the state's public health goals.

The purposes of the program shall be to

1. assist the State-wide Health Information Exchange in establishing and maintaining itself as a neutral and trusted entity that serves the public good for the benefit of all Connecticut residents, including, but not limited to, Connecticut health care consumers and Connecticut health care providers and carriers, p
2. perform, on behalf of the state, the role of intermediary between public and private stakeholders and customers of the Statewide Health Information Exchange, and
3. fulfill the responsibilities of the Office of Health Strategy, as described in section 164 of this act (section 1 of P.A. 18-91).

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Background:
Governance Models

Components of Governance Framework

Source: https://www.healthit.gov/

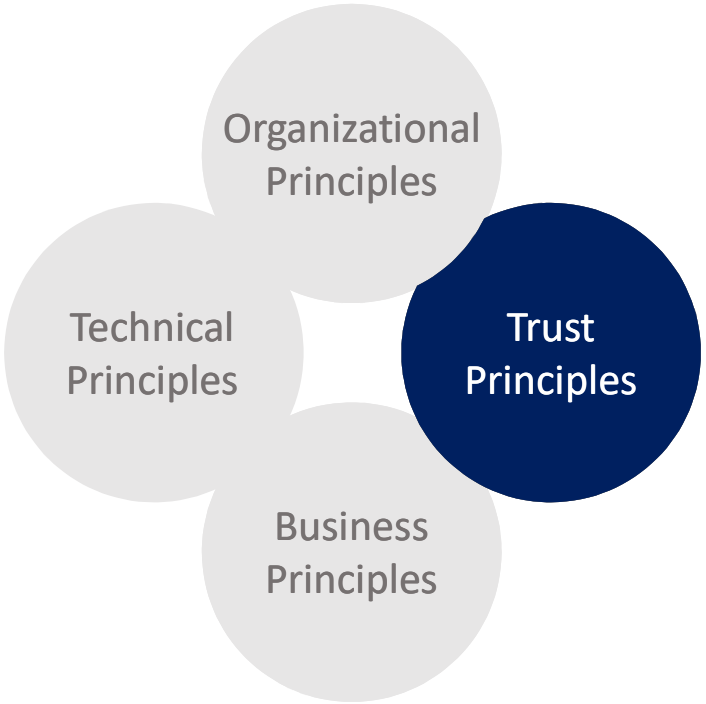
Organizational Principles

- Operate with transparency and openness
- Establish mechanisms to ensure that the entity's policies and practices and adherence to applicable federal and state laws and regulations
- Promote inclusive participation and adequate stakeholder representation, especially patients in the development of policies and practices
- Ensure oversight is consistent and equitable
- Provide due process to the stakeholders to which it provides oversight

Source: https://www.healthit.gov/

Trust Principles

- Public access to “Notice of Data Practices,” including data use agreements
- Explanation of privacy and security policies
- Provide meaningful choice as to whether personally identifiable information can be exchanged
- Request data exchange limits based on data type or source (e.g. substance abuse treatment)
- Ability to access and request changes to personally identifiable information
- Assurance that personally identifiable information is consistently and accurately matched when electronically exchanged



Source: https://www.healthit.gov/

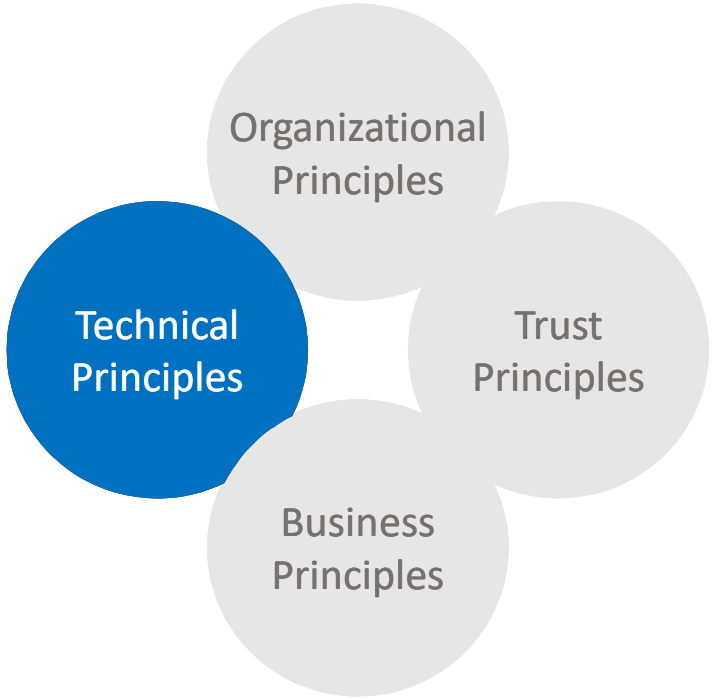
Business Principles

- Set standards of participation that promote collaboration and avoid differences in fees, policies, services, or contracts
- Provide open access to exchange services (e.g. directory data) that would enable partners to identify with whom they can electronically exchange information
- Publish statistics describing their electronic exchange capacity
- Maintain and disseminate up-to-date information about: compliance with relevant statutory and regulatory requirements; available standards; potential security vulnerabilities, and best practices developed for HIE

Source: https://www.healthit.gov/

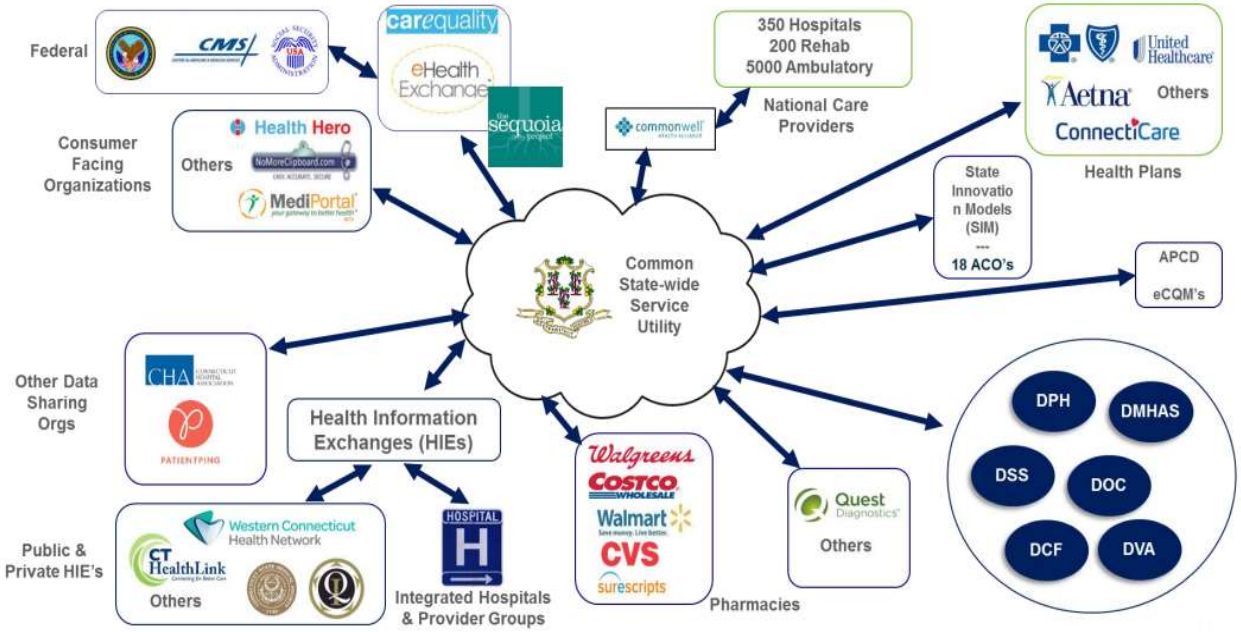
Technical Principles

- Ensure that technology is implemented to support the Trust and Business Principles
- Encourage the use of vocabulary, content, transport, and security standards, and associated implementation specifications developed by voluntary consensus standards organizations (VCSOs) when federal standards have not been adopted
- Lead engagement in VCSOs and national efforts to accelerate standards development and consensus on the adoption of standards as well as the improvement of existing standards.
- Work with VCSOs to develop standards for specific use cases and volunteer to pilot and use new standards when no such standards exist
- Take an active role in development and implementation of conformance assessment and testing methods for HIE and utilize (or promote the use of) testing methods developed to assess compliance with federal standards



Source: https://www.healthit.gov/

Connecticut – "Network of Networks"



Contracted participants will include:

- Individual provider entities (clinics, hospitals, etc.)
- Orgs representing multiple entities (e.g. HIEs)

Uniform contract terms and "rules of the road" apply to all participants and flow down to exchange partners of participants

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Background:
Trust

Trust Framework Purpose

- Common language, understanding, and agreement
- Promotes transparency, trust, and sharing
- Addresses requirements for data use and sharing among a variety of stakeholders
- Fairness
- Accountability
- Privacy & Security
- Minimized need for one-off trust agreements and contracts

What is a Trust Agreement?

- Legal agreements that include Policies and Procedures, BAA's
- Multi-party agreement among participating HIEs that defines how the HIEs relate to each other
- Legal framework within which HIEs can exchange data electronically
- Assumes (requires) that each HIE has trust relationships in place with its participants

Risk if Void a Common Trust

- Impact on data usage and interoperability
- Speed and efficiency scale our exchange efforts
- Healthcare organizations are currently burdened with creating many costly, point-to-point interfaces between organizations which are complex to create, provide oversight, stay in compliance, and maintain, and an inefficient use of provider and health IT developer resources
- Variations in the participation agreements that govern exchange
- No common method for authenticating trust health information network participants
- No common set of rules for trusted exchange
- Terms of non-compliance with an agreement vary, difficulty with oversight
- Many organizations have to join multiple Health Information Networks (HINs), and the HINs do not share data with each other

Trust Framework Analysis of Select Interoperability Initiatives

State-Level

- Michigan (MiHIN)
- Massachusetts (Mass HIway)
- Rhode Island (RIQI)
- New York (SHIN-NY)
- Maine (HealthInfoNet)
- Delaware (DHIN)
- Maryland (CRISP)
- Virginia (ConnectVirginia)
- California (CAHIE)

National

- eHealth Exchange (eHEX), (The Sequoia Project)
- Carequality, (The Sequoia Project)
- Commonwell Health Alliance
- Trusted Exchange Framework and Common Agreement (TEFCA)

Key Differences Between Trust Agreements

- Consent Models
- Breach notification (time requirements)
- Participant Testing/certification/onboarding
- Types of policies and procedures that accompany the trust agreement
- Permitted Purposes
- Use Cases
- Trust agreements vary across end users and HINs forcing end users to join multiple HINs to share data
- Healthcare providers burdened with costs for point-to-point interfaces

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Background:
Relationship of Data Governance to Corporate Governance

Data Governance: Definition

"Data Governance is a system of decision rights and accountabilities for information-related processes, executed according to agreed-upon models which describe who can take what actions with what information, and when, under what circumstances, using what methods."

Data Governance: Guiding Principles

1. Integrity

- Data Governance participants will practice integrity with their dealings with each other; they will be truthful and forthcoming when discussing drivers, constraints, options, and impacts for data-related decisions.

2. Transparency

- Data Governance and Stewardship processes will exhibit transparency; it should be clear to all participants and auditors how and when data-related decisions and controls were introduced into the processes.

3. Auditability

- Data-related decisions, processes, and controls subject to Data Governance will be auditable; they will be accompanied by documentation to support compliance-based and operational auditing requirements.

4. Accountability

- Data Governance will define accountabilities for cross-functional data-related decisions, processes, and controls.

5. Stewardship

- Data Governance will define accountabilities for stewardship activities that are the responsibilities of individual contributors, as well as accountabilities for groups of Data Stewards.

6. Checks-and-Balances

- Data Governance will define accountabilities in a manner that introduces checks-and-balances between business and technology teams as well as between those who create/collect information, those who manage it, those who use it, and those who introduce standards and compliance requirements.

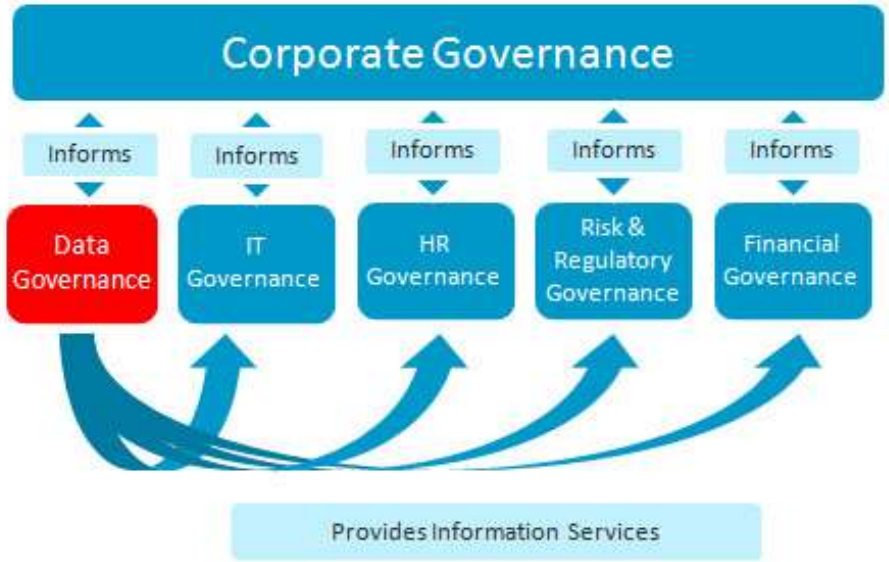
7. Standardization

- Data Governance will introduce and support standardization of enterprise data.

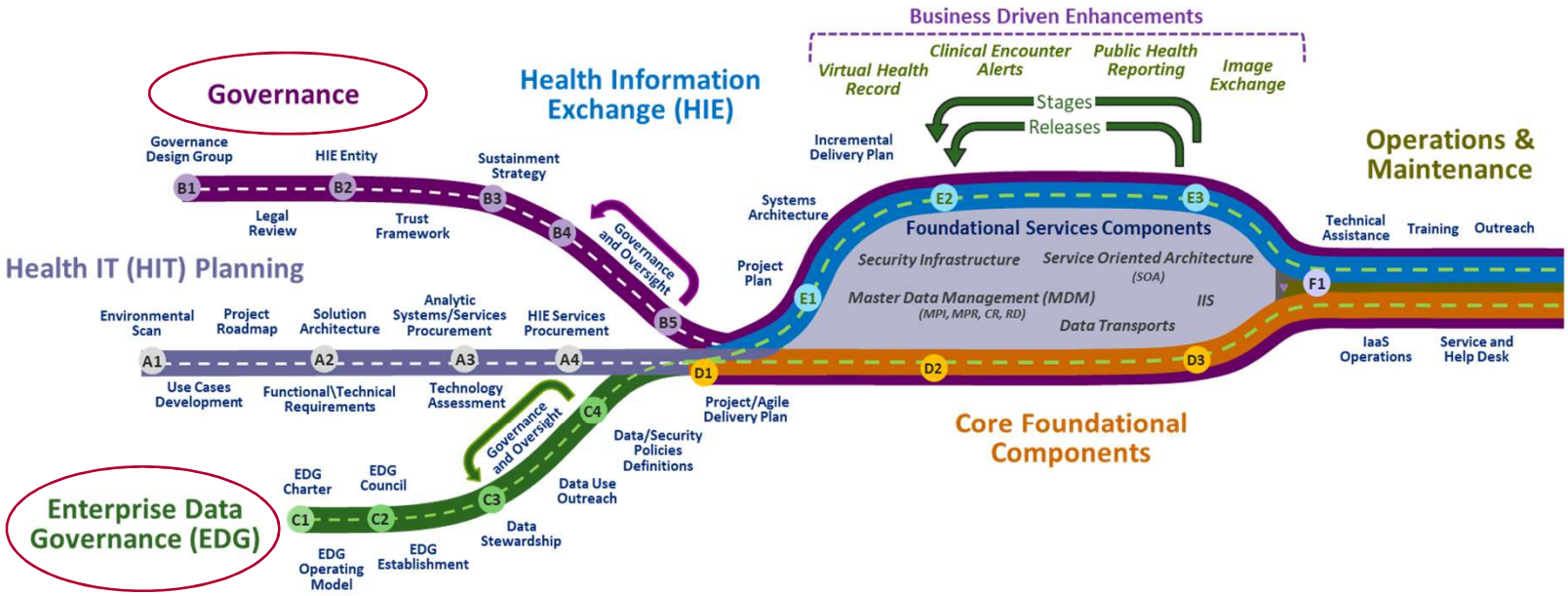
8. Change Management

- Data Governance will support proactive and reactive Change Management activities for reference data values and the structure/use of master data and metadata

Data Governance:
Reference Model for Relationship to Corporate Governance



HIE Activities Roadmap



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Background:
Trust Exchange Framework and Common Agreement (TEFCA)

21st Century Cures Act

- Office of the National Coordinator (ONC) has been working on the **Trusted Exchange Framework and Common Agreement (TEFCA)-** First Draft released January 5, 2018
- The common agreement includes:
  - A common method for authenticating trusted health information network participants;
  - A common set of rules for trusted exchange;
  - Organizational and operational policies to enable the exchange of health information among networks, including minimum conditions for such exchange to occur; and
  - A process for filing an adjudicating noncompliance with the terms of the common agreement**.**

Source: https://www.healthit.gov/sites/default/files/draft-guide.pdf

TEFCA

Why did Congress require the Trusted Exchange Framework?

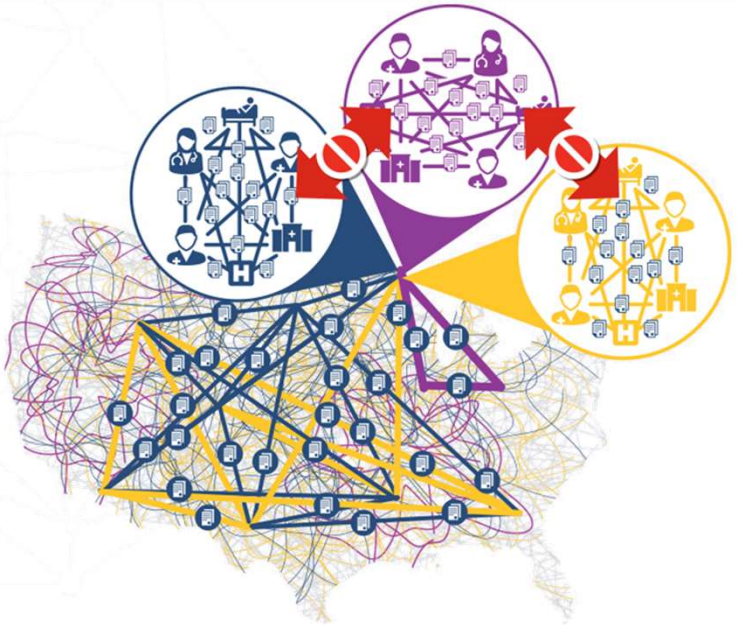
Need for the Trusted Exchange Framework – Complexity

Current Proliferation of Agreements

Many organizations have to join multiple Health Information Networks (HINs), and the HINs do not share data with each other.

Trusted exchange must be simplified in order to scale.

Each line color on the map represents a different network.
There are well over 100 networks in the U.S.



Source: https://www.healthit.gov/sites/default/files/draft-guide.pdf

Goals of the TEFCA

GOAL 1

Build on and extend existing work done by the industry

The Draft Trusted Exchange Framework recognizes and builds upon the significant work done by the industry over the last few years to broaden the exchange of data, build trust frameworks, and develop participation agreements that enable providers to exchange data across organizational boundaries.

GOAL 2

Provide a single "on-ramp" to interoperability for all

The Draft Trusted Exchange Framework provides a single "on-ramp" to allow all types of healthcare stakeholders to join any health information network they choose and be able to participate in nationwide exchange regardless of what health IT developer they use, health information exchange or network they contract with, or where the patients' records are located.

GOAL 3

Be scalable to support the entire nation

The Draft Trusted Exchange Framework aims to scale interoperability nationwide both technologically and procedurally, by defining a floor, which will enable stakeholders to access, exchange, and use relevant electronic health information across disparate networks and sharing arrangements.

GOAL 4

Build a competitive market allowing all to compete on data services

Easing the flow of data will allow new and innovative technologies to enter the market and build competitive, invaluable services that make use of the data.

GOAL 5

Achieve long-term sustainability

By providing a single "on-ramp" to nationwide interoperability while also allowing for variation around a broader set of use cases, the Draft Trusted Exchange Framework ensures the long-term sustainability of its participants and end-users.

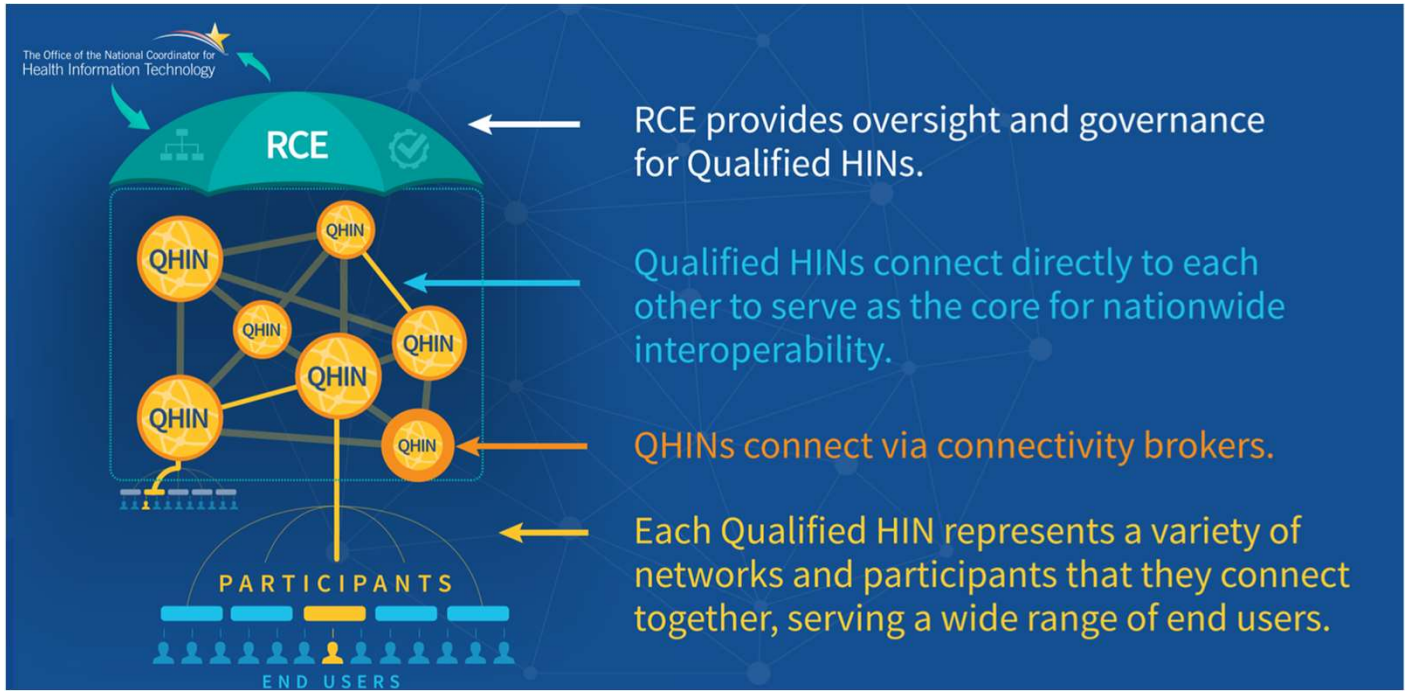
Source: https://www.healthit.gov/sites/default/files/draft-guide.pdf

Part A – Principles for Trusted Exchange

- Principle 1– **Standardization**: Adhere to industry and federally recognized standards, policies, best practices, and procedures
- Principle 2 – **Transparency**: Conduct all exchange openly and transparently
- Principle 3 – **Cooperation and Non-Discrimination**: Collaborate with stakeholder across the continuum of care to exchange electronic health information, even when a stakeholder may be a business competitor
- Principle 4 – **Security and Patient Safety**: Exchange electronic health information securely and in a manner that promotes patient safety and ensures data integrity
- Principle 5 – **Access**: Ensure that patients and their caregivers have easy access to their electronic health information
- Principle 6 – **Data-driven Accountability**: Exchange multiple records at one time to enable identification and trending of data to lower the cost of care and improve the health of the population

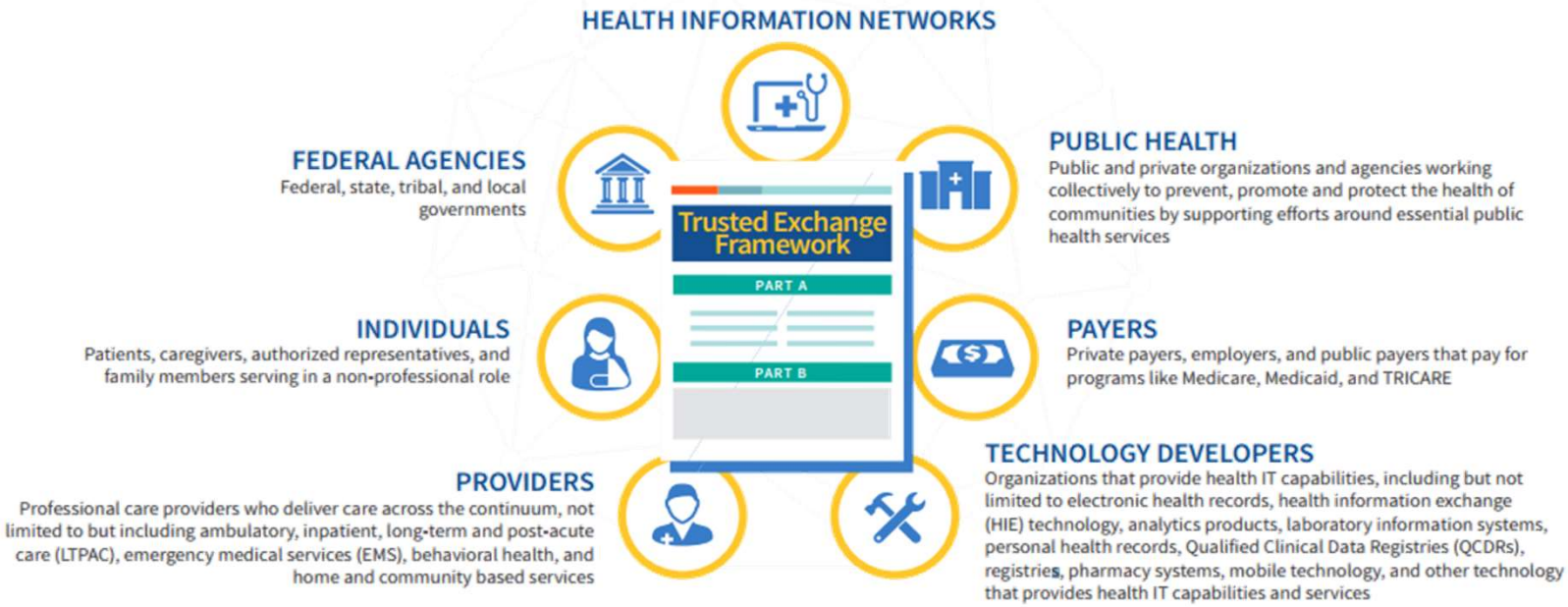
Source: https://www.healthit.gov/sites/default/files/draft-guide.pdf

How will the Trusted Exchange Framework Work?



Source: https://www.healthit.gov/sites/default/files/draft-guide.pdf

Stakeholders Permitted to use TEFCA

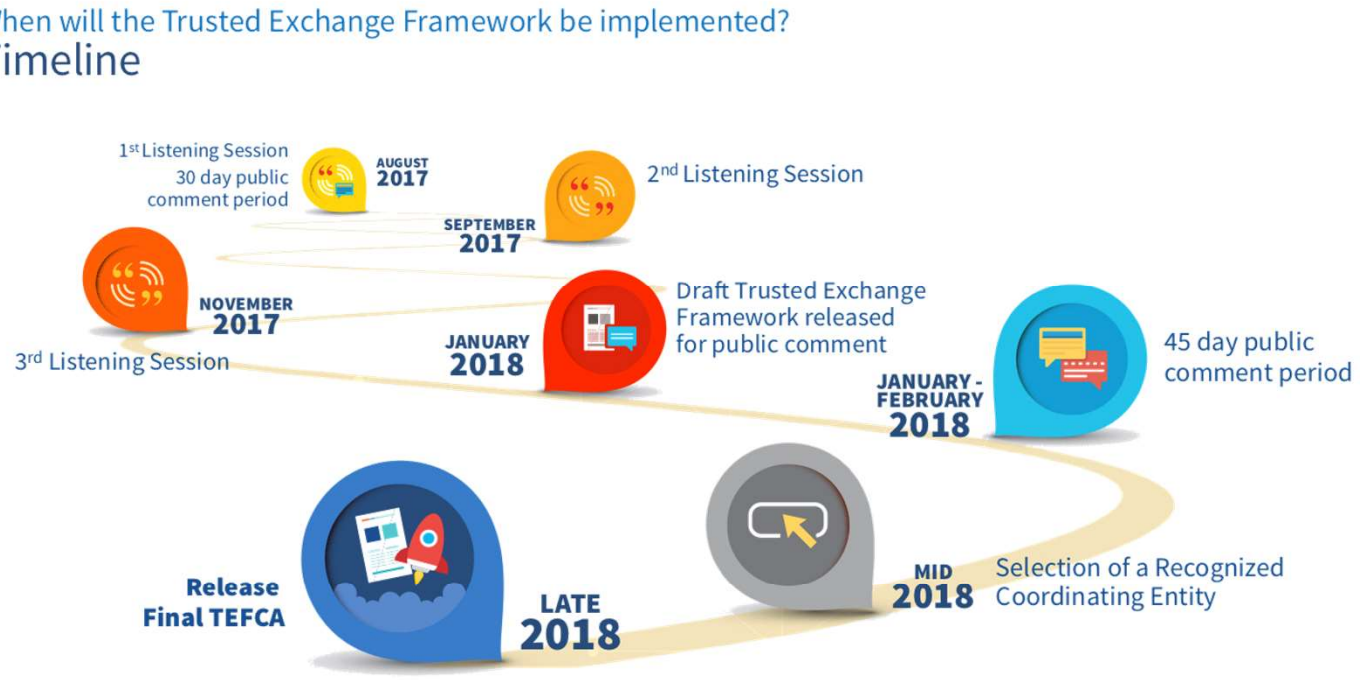


Source: https://www.healthit.gov/sites/default/files/draft-guide.pdf

TEFCA Permitted Purposes

Source: https://www.healthit.gov/sites/default/files/draft-guide.pdf

TEFCA Timeline



Source: healthit.gov

Detailed Recommendations

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Recommendations: Mission, Vision, and Values

Mission, Vision, and Values

The mission, vision, and values of the HIE entity should be informed by recommendations approved by the Health IT Advisory Council in May 2017, and expanded to include the following:

- Keep patients and consumers as the most important stakeholder group and a primary focus in all efforts to improve health IT and HIE (patient as "North Star")
- Leverage existing national and state-based interoperability initiatives
- Implement core technology, such as identity services, that complements and interoperates with systems currently in place
- Build trust by implementing common "rules of the road" that provide a sound policy framework
- Support value-based care initiatives such as ACOs and CINs
- Ensure all stakeholders can participate in standards-based data sharing
- Implement workflow tools that improve efficiency and effectiveness
- Ensure data is meaningful and creates tangible value for stakeholders

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Recommendations:
Critical Success Factors

Critical Success Factors

Factors critical to the success of the HIE entity should be identified, adopted and used to underpin governance, strategy and operations. Initial consideration should be given to the following:

- Alignment with Connecticut statutes
- Alignment with Federal statutes
- Compatibility with national interoperability initiatives, including TEFCA
  - May require alignment of Connecticut statutes
- Stakeholder engagement, support, and participation
- Sustainability supported by stakeholder buy-in and aligned financial incentives
- Foundation for trust
- Reliable, accessible, and secure technology
- Tangible value to stakeholders
- Neutrality, i.e., no competitive advantage to any one stakeholder / segment
- Consumer confidence in the security, confidentiality, and use of their data
- Clear roadmap for HIE development and use case implementation that fosters early participation and ongoing support for those who participate in later use cases

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Recommendations: Characteristics of a Neutral and Trusted Entity

Characteristics of a Neutral and Trusted Entity

The HIE entity serving as the corporate home for HIE should be neutral and trusted. The following are suggested attributes and values for the HIE entity:

To be neutral, the entity should:

- Serve the public good and be of benefit for all Connecticut residents
- Provide no competitive advantage for any group of stakeholders
- Be owned and governed by a party or parties other than the state
- Be governed by an engaged board of directors representing private and public sector leaders with decision-making authority in the organizations that they represent
- Make business decisions based on value-creation, leading to financial sustainability
- Make judicious use of public and private resources
- Balance value creation across stakeholder groups

To be trusted, the entity should:

- Provide a trust framework that establishes clear "rules of the road" including enforcement authority related to compliance
- Be accountable and transparent to stakeholders
- Conduct business based on sound policies and procedures
- Employ a consensus-driven approach for decision-making
- Have transparent contracting and purchasing practices
- Obtain external certification or audit from an information security perspective

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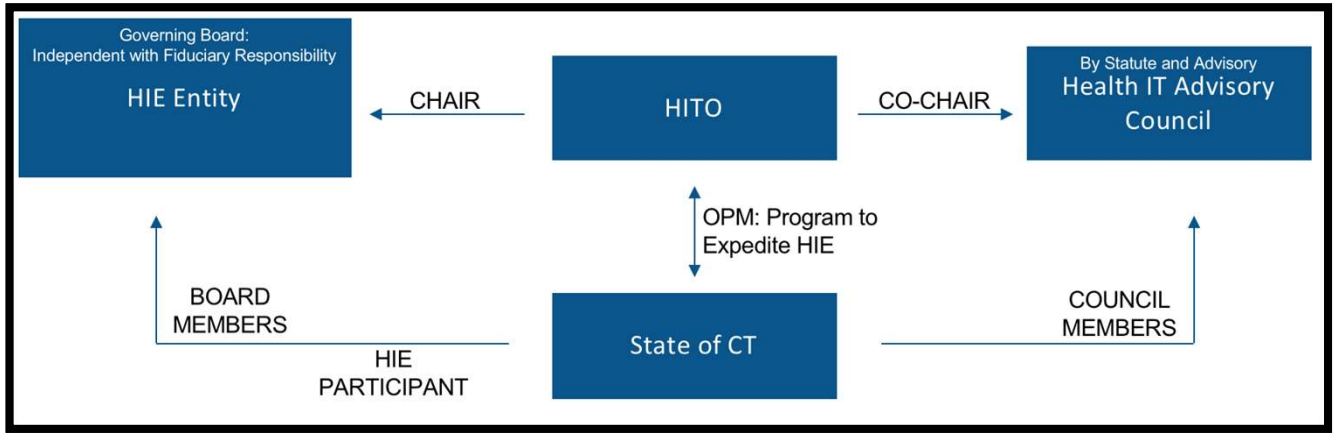
Recommendations: Relationships of Key Parties

Relationships of Key Parties

The relationship of the State of Connecticut to the HIE governance should be clear, transparent and in alignment with Connecticut statutes including PA 17-2. The schematic below should be used to illustrate the set of relationships among the State of CT, the Health Information Technology Officer, the Health IT Advisory Council and the HIE entity.



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Recommendations: Considerations for Creating a New Entity vs. Designating an Existing Entity

Creation of a New Entity vs. Designation of an Existing Entity

A new not-for-profit entity should be strongly considered as the corporate home for HIE services and activities though only after a thorough review of other options (i.e., designation of an existing entity); such review should be undertaken as soon as practicable. Such review should include consideration of the following advantages of each option:

Creation of a New Entity

- No pre-existing perceptions of the organization
- Ability to effectuate statutory intent more easily
- Clear focus and intent of the organization (vs. competing interests of other lines of business)

Designation of an Existing Entity

- Ability to leverage existing infrastructure
- Leadership and staff in place
- Tax-exempt status in place
- Economies of scale

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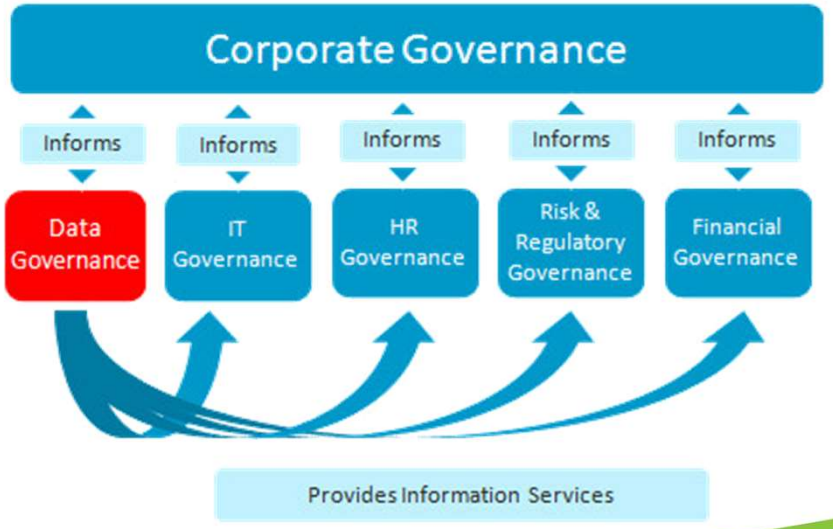
Recommendations:
Data Governance Relationship to Corporate Governance

Data Governance Relationship to Corporate Governance

A robust data governance function is essential for ensuring best practices for handling of data related to health information exchange, analytics and corporate activities. Data governance should be overseen by a Data Governance Council, functioning under the overall corporate governance oversight of the HIE entity, as illustrated by the graphic below.



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Recommendations:
Elements of Trust Agreement

Elements of Trust Agreement

Trust agreements should be developed and implemented that codify "rules of the road" for data sharing and data usage, consistent with Federal and State statutes and regulations, and in conformance with TEFCA.

Elements of the trust agreement should include the following:

- Purpose & Scope
  - Scope of Exchange
  - Approach to Establishing Trust
  - Governance Structure
- Operational Policies/Procedures
- Permitted Purposes
- Permitted Participants
- Identity Proofing & Authentication
- Technical Approach and Infrastructure
  - Standards Used
- Cooperation & Non-Discrimination
- Allocation of Liability and Risk
- Accountability
- Technical
  - Network Flow Down
  - Enforcement
  - Dispute Resolution
- Consent Model
- Transparency
- Privacy & Security
  - Breach Notifications
- Access
- Amendment process
- "Boilerplate" Provisions:
  - Governing Law
  - Venue
  - Severability / Savings
  - Force Majeure
  - Assignment
  - Amendment
  - Independent Contractors / Relationship
  - HIE's relationship to state
  - Notices
- "Boilerplate" Provisions (continued):
  - Entire Agreement
  - Survival
  - Waiver
  - Priority (between other documents)
  - Counterparts
  - No third-party beneficiaries
  - Mediation of HIE-related disputes between participants

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Recommendations: Policies and Procedures Table of Contents

Policies and Procedures Table of Contents

Governance practices should be supported by a robust set of policies and procedures that ensure fiduciary responsibilities and oversight of activities are fulfilled. Policies should be adopted by the Board and procedures should be developed by Management for the following*:

Privacy and Security

- Consent
- Authorization
- Authentication
- Access
- Audit
- Breach
- Compliance
- Sanctions and enforcements
- Cybersecurity
- Specially protected information
- Individual's access and rights
- Auditing and monitoring
  - HIE Entity
  - HIE Participants
- Participant subcontractor requirements
- Permitted purposes
  - Permitted uses
  - Permitted disclosures

Technical and Operational**

- System requirements
- Standards
- Testing and onboarding
- Auditing and monitoring
- Identity management
- Data quality and integrity
- Service Level Agreements (SLA)
- Training
- Help desk

Organizational

- Openness and transparency
- Node eligibility
- Insurance and liability
- Flow-down requirements
- Suspension
- Dispute resolution
- Non-discrimination
- Information blocking
- Fees
- Application review process

**Note that standard corporate P&P, such as those related to finance, were not addressed in these recommendations.*

***Note that these are Policies and Procedures that should be developed for Technical and Operations. In some cases, standards will be adopted for these as well.*

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Recommendations: TEFCA

TEFCA

Governance of health information exchange and data sharing within the State of CT should be conformant with the Trusted Exchange Framework and Common Agreement (TEFCA) currently under development by the Office of the National Coordinator for Health Information Technology (ONC) pursuant to the 21st Century Cures Act.

- The HITO should closely monitor ongoing development of TEFCA to ensure alignment and conformance with CT governance and trust framework; strategic opportunities for participation as either a HIN or QHIN should be identified and assessed.
- The Principles of Trusted Exchange should be endorsed:
  - Standardization
  - Transparency
  - Cooperation and non-discrimination
  - Security and patient safety
  - Access
  - Data-driven accountability
- The final Common Agreement of TEFCA should be taken into consideration in the development of a Trust Agreement by the HIE entity.

Additional Considerations

Additional Considerations

The below additional considerations are not formal recommendations from the Governance Design Group. These additional considerations brought forth by Design Group members were captured as potential future discussion topics for the HIE entity.

- Once established or designated, the HIE entity should make recommendations based on the below activities:
  - Review existing state privacy laws, for HIE adaptation to align with TEFCA and the needs and requirements for statewide data sharing
  - Conduct ongoing monitoring of legislation and market research to ensure policy and strategy alignment
  - Engage in ongoing governance review, including monitoring of the composition and size of the Board of Director

Supplemental Information

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Select Federal Law, State Regulations and Legislation

Compliance with Applicable Federal Laws

- Health Insurance Portability and Accountability Act (HIPAA)
- Privacy Act
- Freedom of Information Act (FOIA)
- Family Educational Rights and Privacy Act (FERPA)
- Federal Torts Claims Act
- Federal Information Security Management Act
- Confidentiality of Alcohol and Drug Abuse Patient Records, 42 CFR Part 2

Health Insurance Portability and Accountability Act (HIPAA) 1996

- HIPAA ***does not*** create legal obstacles for sharing information through an HIE in that it ***does not require*** a covered entity to obtain member/patient consent prior to sharing or disclosing information with other covered entities through an HIE
- HIPAA ***contains exceptions*** that allow a covered entity to share information (without consent) for treatment, payment or healthcare operations
- The primary exception under HIPAA is the sharing of psychotherapy notes.
- There maybe consent requirements under other federal or state laws for "Sensitive" Data such as, behavioral health and substance abuse

HIPAA vs. State Law

- HIPAA preempts state laws that permit disclosure unless the state law is “more stringent” than HIPAA
- “More stringent” means the law provides a higher level of patient privacy protection
- HIPAA allows all disclosures required by state law
- Typical state law restrictions that go beyond HIPAA include laws governing genetic information, mental health records, substance abuse records, human immunodeficiency virus records, and informed consent
- These restrictions could lead to entire records being excluded from HIEs, as data-aggregating software used by HIOs does not always have the capability to redact only the sensitive information
- To combat these roadblocks, HIOs are working to:
  - Make granular data restrictions on the display of sensitive information
  - Engaging in lobbying and lawmaking efforts to soften certain state law restrictions that make HIE operation costly and burdensome

Source: https://www.mcguirewoods.com/news-resources/publications/health_care/HIT-News-April2014.pdf; https://www.hhs.gov/hipaa/index.html; https://www.hhs.gov/hipaa/index.html

Connecticut Statutes

- Disclosure of personally identifiable information by state agencies to the Connecticut Health Information Network – C.G.S. § 19a-25f
  - State agency participants in the Connecticut Health Information Network "may disclose personally identifiable information held in [their] databases to the administrator of the Connecticut Health Information Network and its subcontractor" in order to develop the network. Such disclosure must occur in compliance with state and federal laws (e.g. HIPAA and FERPA)
- Availability of patient information to certain agencies – C.G.S. § 17b-225
  - The Department of Public Safety, Department of Social Services, and the U.S. Department of Health and Human Services ("Departments") may access patient information from hospitals and facilities operated by the Department of Public Health, Department of Development Services, and Department of Mental Health and Addiction Services ("Agencies") to the extent that the information is necessary to pay for patient care, claim federal reimbursement, or conduct an audit of federally funded programs.
- APCD – § 38a-1091 of the 2018 supplement of the general statutes, as amended by P.A. 18-91
  - Allows for data in APCD to be available to any state agency, insurer, employer, health care provider, consumer of health care services, researcher or the Connecticut Health Insurance Exchange for the purpose of allowing such person or entity to review such data as it relates to health care utilization, costs or quality of health care services. Disclosure of APCD data shall be made in a manner to protect the confidentiality of health information, as defined in 45 CFR 160.103, and other information, as required by state and federal law (e.g., HIPAA, ERISA). Access to de-identified data or limited data set requires application for data, data use agreement, waiver, etc.

Connecticut Statutes Continued

- Data submission requirements - C.G.S. § 19a-654(b), as amended by P.A. 18-91
  - Each short-term acute care general or children's hospitals shall patient-identifiable inpatient discharge data and emergency department data to the [Office of Health Care Access division] Health Systems Planning Unit of the [Department of Public Health] Office of Health Strategy to fulfill the responsibilities of the [office] unit. Such data shall include data taken from patient medical record abstracts and bills. The [office] unit shall specify the timing and format of such submissions. Data submitted pursuant to this section may be submitted through a contractual arrangement with an intermediary and such contractual amendment shall (1) comply with the provision of HIPAA 104-191, and (2) ensure that such submission of data is timely and accurate. The [office] unit may conduct an audit of the data submitted through such intermediary in order to verify its accuracy.
- Data submission requirements for the Office of Health Care Access (OHCA) – C.G.S § 19a-654(d), as amended by P.A. 18-91
  - Except as provided in this subsection, patient-identifiable data received by the **[**office**]** unit shall be kept confidential and shall not be considered public records or files subject to disclosure under the Freedom of Information Act, as defined in section 1-200. The **[**office**]** unit may release de-identified patient data or aggregate patient data to the public in a manner consistent with the provisions of 45 CFR 164.514. Any de-identified patient data released by the **[**office**]** unit shall exclude provider, physician and payer organization names or codes and shall be kept confidential by the recipient. The **[**office**]** unit may release patient-identifiable data (1) for medical and scientific research as provided for in section 19a-25-3 of the regulations of Connecticut state agencies, and (2) to (A) a state agency for the purpose of improving health care service delivery, (B) a federal agency or the office of the Attorney General for the purpose of investigating hospital mergers and acquisitions, or (C) another state's health data collection agency with which the **[**office**]** unit has entered into a reciprocal data-sharing agreement for the purpose of certificate of need review or evaluation of health care services, upon receipt of a request from such agency, provided, prior to the release of such patient-identifiable data, such agency enters into a written agreement with the **[**office**]** unit pursuant to which such agency agrees to protect the confidentiality of such patient-identifiable data and not to use such patient-identifiable data as a basis for any decision concerning a patient. **No individual or entity receiving patient-identifiable data may release such data in any manner that may result in an individual patient, physician, provider or payer being identified. The [office] unit shall impose a reasonable, cost-based fee for any patient data provided to a nongovernmental entity.**

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Health IT Advisory Council Website:

http://portal.ct.gov/Office-of-the-Lt-Governor/Health-IT-Advisory-Council