Governance Design Group Session #2
Meeting Summary

Meeting Date	Meeting Time	Location – Zoom Web Conference
Wednesday, May 23, 2018	10:00am – 11:30am EDT	**Webinar link:** https://zoom.us/j/815997759 **Telephone**: (408) 638-0968 or (669) 900-6833 **Meeting ID:** 815 997 759

Design Group Members			
Lisa Stump, MS, RPh, *Yale New Haven Health*	X	**Bruce Adams, JD,** *Office of the Lieutenant Governor*	
Patricia Checko, DrPH, *Consumer Advocate and Public Policy Professional*	X	**Commissioner Roderick Bremby,** *Department of Social Services Representative (supported by Polly Bentley and Joe Stanford, as needed)*	X*
Jake Star, *VNA Community Healthcare & Hospice*	X	**Bill Roberts, JD,** *Office of the Attorney General (on assignment from Shipman & Goodwin)*	X
Design Group Support			
Michael Matthews, CedarBridge Group	X	M.J. Lamelin, HIT PMO	X
Chris Robinson, CedarBridge Group	X	Sarju Shah, HIT PMO	X
Jennifer Richmond, HIT PMO	X	Kelsey Lawlor, HIT PMO	X
Grace Capreol, HIT PMO	X	Dino, Puia, HIT PMO	X

*Polly Bentley and Joe Stanford attended as DSS representatives

Minutes		
	Agenda Topic	**Notes**
1.	**Welcoming Remarks – Meeting Overview and Objectives**	Jennifer Richmond provided welcoming remarks and reminded people that these meetings are open to the public and that each meeting will be recorded. All questions can be directed to Jennifer. Jennifer then introduced Bill Roberts, who is representing the Office of the Attorney General (OAG). Bill has listened to the meeting recording from session #1 and met separately with Michael Matthews and Jennifer Richmond to get up-to-speed. Bill Roberts is on assignment to OAG from Shipman & Goodwin, where he is a Partner. Bill works with data privacy and has worked on the APCD with Access Health CT. Bill is excited to take some of his past experiences and help think through solutions for CT. There were minor changes to the Project Charter, which has been redistributed to the group. Commissioner Bremby was added as the Design Group member representing the Department of Social Services (DSS) and will be supported by Polly Bentley and Joe Stanford. Jennifer asked Design Group members if there were any issues with the changes to the Project Charter. No issues were reported by Design Group members. The Project Charter will now be sent to Allan Hackney (Project Sponsor) for his signature.
2.	**Recap of Prior Meeting (May 23) and Approval of Meeting Summary**	Michael Matthews provided an overview of what was discussed during the first Design Group meeting on May 23, 2018. This discussion included background of this Governance Design Group and relevant context from the State of Connecticut, Design Group timelines, critical success factors, and expectations. The first Design Group meeting also started the discussion

		around HIE Governance Basics. This is where Michael will pick back up the presentation during today's meeting (Slide 23). Michael requested a vote to approve the Governance Design Group Session #1 Meeting Summary, which was distributed to members on Monday, June 4. The Meeting Summary was approved unanimously without changes.
3.	**HIE Governance Basics (continued from May 23rd meeting)** • *Principles* • *Trust* • *Policies & Procedures* • *Organizational* • *National Perspectives* • *State Perspectives*	Michael is picking the presentation back up on Slide 23 "Connecticut – Network of Networks." At the end of the last meeting we were talking about Trusted Exchange Framework and Common Agreement (TEFCA) and some of the national interoperability initiatives. This slide will help set the stage for some of the things we will be talking about today and in future sessions. Michael brought up the concept of Metcalfe's Law, which relates to telecommunications networks. Metcalfe said that the value of a network is proportional to the square of the number of users. For example, if there are a small number of people in a network, then users won't be able to derive much value, but the value will multiply geometrically as the number of participants increase. Nationally, there are a number of initiatives currently that have connected regional and state entities and providers together across HIE enterprises. When we think about an HIE as a noun today, there is both a vertical and horizontal dimension. For example, when the Connecticut statewide HIE is stood up, it will not be working solely within Connecticut; it will be interacting with entities regionally and across the country. There will also be a vertical dimension to the HIE ecosystem. When TEFCA is stood up, there will be a Recognized Coordinating Entity (RCE) at the top of the vertical, which will determine the rules of the road. Then the Qualified Health Information Networks (QHINs) will abide by the rules of the RCE, while further defining requirements for their participants. Health Information Networks (HINs) will fall within the governance and rules of the road of the QHINs. One can see the complexity and power of the vertical/horizontal structure of data exchange. Tying back to Metcalfe's Law, this complexity creates the multiplier effect on value when you have a network of networks. Critical to this group is the concept that everyone is playing by the same rules of the road. Part of the governance work in Connecticut is understanding that the rules of the road, overall, need to be aligned at the national level, but also mindful of what is unique about Connecticut. There still needs to be enforcement mechanisms and policy considerations at the state level, such as consent. For example, CommonWell, Carequality, and eHealth Exchange do not define what consent model needs to be adopted; there is a principle of local autonomy. Connecticut will also need to establish roles-based access. Some HIEs only allow providers and nurses to have access to data. Other HIEs, may allow administrative and clerical roles to access demographic information for billing purposes. The last example is around permitted purposes. Some HIEs dictate treatment as the only permitted purposes, while others align with the permitted purposes defined

		by HIPAA (treatment, payment and operations), and others will include other purposes, such as batch-query for public health. Over the next couple of meetings, we will be discussing a number of topics. For example, non-discrimination will need to be discussed to ensure all participants in exchange are treated equally with respect to data access. Also, there is a notice of proposed rulemaking around information blocking that is expected to be released this summer. There will also be further guidance on TEFCA and its implications. Last meeting, Commissioner Bremby had some questions about The Sequoia Project. Some of you may remember the term Nationwide Health Information Network (NHIN), which was changed to the eHealth Exchange a few years ago. NHIN was created by the Office of the National Coordinator. All participants under NHIN agree to the Data Use and Reciprocal Support Agreement (DURSA) to exchange information. Michael was the CEO of MedVirginia, which was one of the first two Participants to exchange data (with the Social Security Administration) under NHIN. A few years ago, the operations of eHealth Exchange were privatized under The Sequoia Project. eHealth Exchange is governed by the Coordinating Committee, whose powers are defined and codified within the DURSA. They establish policies and procedures, testing results, etc. The eHealth Exchange now has over 200 participants, including Yale New Haven, The Department of Veterans Affairs, Department of Defense, the Social Security Administration, and 59 regional and statewide HIEs, representing over 120 million unique patients. Undoubtedly Connecticut will want to tap into this network. Carequality is newer than eHealth Exchange; it was launched three years ago. It is not a network, it is a network-of-networks framework. If a network complies with the rules of the road, then these networks will be able to communicate with other networks. Carequality has grown dramatically. CommonWell is a vendor-led network with Cerner, Allscripts, Greenway, and athenahealth being some of the founding members. We are starting to see a collaboration across these initiatives. eHealth Exchange is becoming a Carequality implementer. Likewise, CommonWell signed the implementer agreement with Carequality so that any participant in the CommonWell alliance can exchange with anyone within Carequality or eHealth Exchange. Lisa Stump Comment – thank you, Michael. This was important context and you provided a good detailed overview and framing for the work that this group will do over the next several meetings. Michael introduced the next slide, which provides a state example from Michigan. This is a good case study for Connecticut to reference. Michigan Health Information Network (MiHIN) Shared Services is a highly successful HIE and has spent a long time on defining their value proposition and attends to governance issues quite well. They operate a network-of-network

		approach. There is a Health IT Commission created by the Michigan legislature which is similar to Connecticut's Health IT Advisory Council. As a side note, MiHIN's wholly-owned subsidiary, Velatura, is a management consulting organization that is currently supporting the Office of Health Strategy. MiHIN has a Chain of Trust (Slide 25) where everyone is operating under common rules of the road. Next, we will look at Trust Agreements (Slide 27) in more detail. Sometimes the term Trust Framework is used more broadly to refer to not just the Trust Agreements, but also the common language, understanding, and agreement; promotes transparency, trust, and sharing; addresses requirements for data us and sharing among a variety of stakeholders; and fairness and accountability to minimize the need for one-off contracts. There can be only one version of the data sharing Trust Agreement in place. In the eHealth Exchange, there is not one difference between the 200+ signed DURSAs. If one entity is able to negotiate a different provision, then the whole system of trust breaks down. Right now, the DURSA is undergoing a very structured amendment process, which will need sign-off from the Coordinating Committee and Participants. If there is not a common Trust Agreement, then there will not be common trust amongst participants (Slide 28). If there is not common trust, then many organizations have to join multiple HINs, which will have limited ability to share data with one another. There are roadblocks to a single agreement (Slide 29). Certainly, state and federal laws play a role here. We are lucky to have Bill and Bruce as part of the Design Group. Consent models are another thing to keep in mind as we structure an agreement that works for Connecticut and is in-synch with the other initiatives Connecticut wants to take advantage of. We talked a little bit about the CSMS HIE as an example during last meeting. The CSMS HIE may become a node on the state-wide HIE, and we will need to make sure they have the authority to sign the Connecticut agreement and assign those provisions down to their end users. The Trust Agreement (Slide 31) is a legal agreement that includes requirements to comply with adopted policies and procedures, business associate agreements, etc. This is generally a multi-party agreement that provides the legal framework within which HIEs can exchange data electronically and requires each HIE has a trust relationship in place with its participants. Michael gives big kudos to Jennifer Richmond and Grace Capreol for their development an exhaustive analysis of Trust Agreements and relevant state-level provisions. This is an excellent compilation of documents, approaches, and where there are commonalities/differences between Trust Agreements. This will be a homework assignment for the Design Group members. We will also provide actual examples of such documents for your review.

The major components of a Trust Framework and Trust Agreement (Slide 33) include:

- Purpose and scope (scope of exchange, approach to establishing trust, governance structure, operational policies and procedures)
- Permitted purposes (treatment, payment, operations, public health, authorization-based disclosures as illustrated by the Social Security Administration's disability determination use case)
- Permitted participants (e.g., health systems or payers)
    - There is a priority for a payer value proposition and their participants at the national level. Payers and HIEs have had an awkward dance in other states, but this is developing and there is a commitment in Connecticut to figure this out.
    - Another question is whether a vendor can be a participant in an HIE. If a vendor is willing to sign the DURSA, then most people take a broader view. Carequality and CommonWell have figured out a path forward for how vendor-driven networks can participate effectively.
- Identity proofing and authentication
    - HIEs need to know that data is being accessed only by authorized users.
- Technical approach and infrastructure (standards)
- Cooperation and non-discrimination
- Allocation of liability and risk
    - This is huge. In this context, the allocation of liability has to do with examples such as if one organization sends their data appropriately to a different organization, who then does something inappropriate with the data, the liability is on the receiver end. If there is an issue on the sender, such as inappropriate disclosure, then this liability needs to be with the sender.
- Accountability (technical, network flow down, enforcement, and dispute resolution)
    - It is one thing to have rules of the road, but what happens when the rules are violated? HIEs need to have enforcement mechanisms and the ability to suspend or terminate participants.
    - Dispute resolution is usually defined and there is usually arbitration.
- Consent model – this will be a lengthy conversation, not for this Design Group, but for the HIE when it is stood up.
- Transparency

		• Privacy and security (including breach notifications) • Access One of our exercises in the future will be to define the elements of a Trust Agreement. We will not define the permitted purposes, for example, but we will recommend elements that should be addressed such as permitted purposes. This slide shows key differences between Trust Agreements (Slide 34). There are time requirements around breach notifications. This is defined by the DURSA. Use cases is another interesting difference. Our colleagues from Michigan can speak to this if it is an area of interest for the group. They have gotten this right with a core Trust Agreement with mandatory use cases, and they separate optional use cases at the discretion of the participant. We talked about TEFCA at the last meeting, but Michael wants to cover a couple of the schematics again. TEFCA is part of the 21st Century Cures Act (Slide 36) and there are two components: The Trusted Exchange Framework and the Common Agreement. Slide 37 shows ONC's concept what health information exchange looks like today. The Principles for Trusted Exchange (Slide 38) shows some terms that you have been hearing already – standardization, transparency, cooperation and non-discrimination, etc. We talked about the importance of patient access in the HIE Use Case Design Group. The patient portal was determined to be a Wave 2 Use Case, not because it was not important, but because the Design Group felt there was prerequisite functionality that needed to be implemented before a patient portal could be viable. This was more of a timing issue. Also noted was "data-driven accountability." What is contemplated here is the idea of being able to expand the concepts of data acquisition to not just be patient-by-patient, but to be able to query for populations of patients to be able to support value-based care and population health. This is something that sounds great but exceeds the technical capability of most HIEs and EHRs today. Lisa Stump Question – what I don't see here is the timeliness of exchange, meaning is this intended to be or are we expecting to include real-time data exchange? You were implying on-request and nightly batches, should we have some principle that addresses this? Michael Response – Let me be clear, the principles on this slide are from TEFCA. In that context, it is near-real-time on the patient-by-patient basis, but this is not practical on the population-level use cases and batch exchanges. This whole service-level expectations around exchange and what is an appropriate amount of time, this will be something that we can make some statements on in our

		recommendations. Absolutely, this is within the purview of this Design Group. Slide 39 shows the goals of TEFCA. Some important goals to highlight are goal #4 "Build a competitive market allowing all to compete on data services" and goal #2 to "provide a single on-ramp to interoperability for all." Slide 40 shows the stakeholders who are permitted to use the TEFCA. Slide 41 gets into the verticality which Michael was discussing previously. The RCE is at the top, which has not yet been named via RFP or funding opportunity announcement to specify the requirements. This selection will probably be done over the summer, and then the RCE will work with ONC to finalize TEFCA. The RCE establishes the common agreement, then the QHINs and HINs further define the requirements on their particular participants. The TEFCA Timeline (Slide 43) shows that a lot will happen over this summer. Hopefully sometime in late 2018 we will see the release of the final TEFCA. The next few slides will cover federal and state laws, regulations, and legislation. Michael urges Design Group members to read through their homework assignments to get a better understanding of what will be covered in the next few slides Compliance with all applicable laws will be important, including HIPAA and FERPA (if schools are participating). States are allowed to have provisions that are more stringent than HIPAA. Connecticut statutes of relevance, including the APCD, have been identified as baseline state statutes. Bill is on stand-by to bring into account anything that emerges from the current session.
4.	**Building Block Exercises and Discussion** • *Overview of all exercises* • *Critical Success Factors (exercise and discussion)* • *Characteristics of a Neutral and Trusted Entity (exercise and discussion)*	For the rest of the call, Michael wants to start our Building Block Exercises (Slide 50). Earlier, we mentioned that during the next three meetings we will have building blocks for our recommendations to the Health IT Advisory Council. These building blocks will be developed over the course of 9 exercises, which are listed on the slide. We want to complete specific units of work where we present the concept, have a discussion, and capture information in real-time on the screen, and define what constitutes each building block. The recommendations that go to the Advisory Council in July will largely consist of what comes out of these exercises. We will also keep track of issues that are raised, such as Lisa's comment on real-time vs. batch. This is something that may go into a policy or procedure, where we recommend an operating procedure. The exercises will include (Slide 50): • Critical success factors • Characteristics of a neutral and trusted entity • Elements of a trust agreement

- Policies and procedures table of contents
- Relationship of state / HIE entity / Health IT Advisory Council
- Relationship of governance vs. data governance
    - Alan Fontes is listening on these calls and has responsibility for the eCQMs and data analytics work streams.
- Pros and cons of a new company not-for-profit vs. the designation of an existing not-for-profit entity
- Potential impact of TEFCA
    - This has been put towards the end of the exercises, in case ONC releases any additional information.
- Mission and vision considerations
    - We will finish how we started; there will be a mission and vision of the HIE, but we will not be crafting the mission and vision. However, the HIE entity will benefit from thoughts and recommendations of this Design Group.

The first exercise will be the Critical Factors for Success in Connecticut (Slide 51). Some of the existing success factors that are listed go without saying, but it is important that we capture these nonetheless. Success factors that have already been identified include: alignment with state and federal statutes; compatibility with national interoperability initiatives; stakeholder engagement, support, and participation; sustainability; and the foundation for trust.

First, before any additions, are there any questions, concerns, or comments with the existing list? There were no comments. Michael asked if members were okay if this list was included. Lisa Stump agreed that they are fine to include.

Next, Michael asked the Design Group if there were any additions:

- Lisa Stump – I think my suggestion is table stakes for any entity housing PHI; the technology needs to be reliable, accessible, and secure.
    - Michael – thank you for that addition, this is spot on.
- Lisa Stump – I agree including stakeholders, but do we need to be more explicit? The value to stakeholders is important. If this does not deliver value, then this will not be sustainable or successful.
    - Michael – that is a nice addition.
- Bill Roberts – I wanted to suggest adding “neutrality.” Many of the participants will be competitors or will be in a market positioned adverse to one another and we want to make sure the HIE is not favoring one provider or sector over the other.
    - Michael – this is really important.

		• Pat Checko – On the part of the consumer, and their perception of value, I think the whole idea of confidentiality vs. privacy becomes a key priority. Consumers need to feel comfortable that their data is safe and appropriately used.
		  ○ Michael – Absolutely.
		• Jake Star – We need to have some kind of clear roadmap for how the HIE will be built out. We have certain use cases that will be first, and others that will come later, but we want all stakeholders to participate from an early stage, so we need a clear benefit. Stakeholders who won't benefit immediately need to know they will see some benefit down the road.
		  ○ Michael – this is really helpful, thank you.
		
		Michael says that this is a great list and that we will re-visit this at the beginning of the next meeting to make sure it accurately represents the feelings of the group.
		
		Michael then teed up the next exercise: Characteristics of a Neutral and Trusted Entity (Slides 52 – 55). The concept of a neutral and trusted entity was referenced in the environmental scan recommendations and built upon in Public Act 17-2.
		
		Next meeting, we will try to get through three more exercises and we will distribute some meeting materials that should be reviewed in advance. This was a terrific conversation.

5.	**Meeting Wrap-up and Next Steps**	Jennifer thanked everyone for participating. We were looking to take a poll for Design Group members to reschedule meeting #4. We want to move this meeting from June 27th to June 20th (10am – 11:30am). Participants completed the poll: • 7 respondents are okay with the June 20th time frame • 1 respondent is unavailable on June 20th We will be sending out homework assignments in advance of the next meeting. Also, if there are any comments or questions, please feel free to reach out to Jennifer or Michael.

Action Item	Responsible Party	Due Date
Reschedule meeting #4 for June 20th	CedarBridge Group	6/7/18
Distribute meeting materials for Session #3	HIT PMO	6/11/18