

# Health Information Technology Advisory Council

## Meeting Minutes

MEETING DATE	MEETING TIME	Location
March 21, 2019	1:00PM – 3:00PM	Hearing Room 1C, Legislative Office Building 300 Capitol Ave, Hartford CT

### COUNCIL MEMBERS

Allan Hackney, HITO (Co-Chair)	x	Sandra Czunas, OSC	x	Jeanette DeJesus	
Joseph Quaranta (Co-Chair)	x	Mark Schaefer, SIM	x	Robert Blundo, AHCT	T
Joe Stanford, DSS	x	Bruce Metz, UCHC CIO	x	Lisa Stump	
Mary Kate Mason, DMHAS		Ted Doolittle, OHA	x	Patrick Charmel	x
Cindy Butterfield, DCF	x	David Fusco	x	Alan Kaye, MD	T
Cheryl Cepelak, DOC		Nicolangelo Scibelli	x	Dina Berlyn	x
Vanessa Hinton, DPH		Patricia Checko	x	Tekisha Everette	x
Dennis C. Mitchell, DDS	x	Robert Tessier		Patrick Troy, MD	
Mark Raymond, CIO	x	Robert Rioux		Stacy Beck	x

### SUPPORTING LEADERSHIP

Victoria Veltri, OHS		Tom Agresta, MD, UConn Health	x	Chris Robinson, CedarBridge	
Sarju Shah, OHS	x	Kate Hayden, UConn Health	x	Tim Pletcher, Velatura	x
Sabina Sitaru, HIE Entity	x	Carol Robinson, CedarBridge	x		
Alan Fontes, UConn AIMS		Michael Matthews, CedarBridge	x		

### Minutes

	Topic	Responsible Party	Time
<b>1.</b>	<b>Welcome and Call to Order</b>	<b>Allan Hackney</b>	<b>1:00 PM</b>
	Allan Hackney welcomed the Health Information Technology (Health IT) Advisory Council and called the meeting to order. Allan took roll call of Council members and provided an overview of the meeting agenda.		
<b>2.</b>	<b>Public Comment</b>	<b>Attendees</b>	<b>1:05 PM</b>
	There was no public comment.		
<b>3.</b>	<b>Review and Approval of February 21, 2019 Minutes</b>	<b>Council Members</b>	<b>1:10 PM</b>
	Once a quorum was established, the Advisory Council voted to approve the meeting minutes from February 21, 2019. Mark Raymond created the motion to approve the minutes, and Bruce Metz seconded the motion. The motion to approve the meeting minutes was passed without objection or abstentions.		
<b>4.</b>	<b>Announcements</b>	<b>Allan Hackney</b>	<b>1:15 PM</b>
	Allan Hackney announced the departure of Sarju Shah who is taking a new job at the University of Connecticut. Allan thanked Sarju for her contributions and dedicated support of OHS's mission and projects.		
<b>5.</b>	<b>Genomics and Precision Medicine Workshop</b>	<b>Michael Murray</b>	<b>1:25 PM</b>
	Allan Hackney introduced Michael Murray who leads the clinical activities at the Yale Genomics center and helped support the workshop with the Office of Health Strategy (OHS). Michael provided an overview of the "Incorporating Genomic Medicine into Connecticut's Health Information Exchange (HIE)" Workshop, which occurred on March 8, 2019. Michael thanked Velatura and Polly Painter who helped support the workshop.		
	The Yale Center for Genomic Health will be launching The Generations Project later in 2019 as an approach to find better ways to keep people healthy and to help them when they are sick. This project will recruit at least 100,000 volunteers to join this project in an effort to link DNA variants to human health and disease. All		

participants will undergo DNA sequencing and participants will receive back high value results, including cancer risk, heart disease risk, pharmacogenomics, and more. The project will seek ways to engage patients, providers and researchers from other institutions in the state. Yale received a \$9 million grant in 2017 to fund the project.

The Workshop objectives included the following:

- Discuss opportunities for Connecticut to advance as a national leader in genomic medicine and information exchange by leveraging innovative architecture and local subject matter expertise;
- Outline practical and achievable proposals to incorporate genomic medicine in statewide HIE; and
- Initiate Use Case Factory® stage-gate methodology (developed by Velatura) to identify practical “starter set” opportunities to prototype genomics in HIE.

Highlights from the Workshop included:

- Presentations from Genomic Medicine and Connecticut HIE leaders regarding the changing landscape and opportunities of Genomic Medicine and HIE in Connecticut;
- Panel Q&A session including Medicaid, Family Physician, Genomic Medicine, and OHS;
- Two persona-based case studies to identify care paths with and without sharing genetic testing information;
- Identification of opportunities to share genetic testing information with patients, providers, health plans, and others through the case studies; and
- Development of “elevator pitch” for initial ideas to investigate in Use Case Factory™ process and each participant “invested” into their top ideas.

The high-value, practical use case ideas that emerged from the Workshop included:

- Support for prior-authorization of genetic testing by gathering relevant information through HIE;
- Clinical Decision Support (CDS) engine;
- Standardization of genomic data so its actionable for CDS; and
- Ability to query the location of genomic information through participant EHRs.

As a next step, a white paper will be developed to frame high-value, practical genomic medicine use case ideas, initiating Use Case Factory™ process, and a working group will be convened to define details of use case ideas and provide input during the use case development process.

A goal at the beginning of this project was for Connecticut to become a national leader in genomic medicine and information exchange through practical and achievable proposals. Michael explained the ovarian cancer use case is one example of an area of improvement. Michael proposed Connecticut’s 100 x 2020 Campaign for Connecticut to achieve and sustain a month-by-month 100% success rate in offering genetic testing to all women diagnosed with ovarian cancer by December 2020.

Pat Checko asked about the insurance coverage for genetic testing and whether or not this is one of the reasons why women are not receiving this service. Michael stated that there would need to be work done in this area to better understand the landscape. Michael said that there are criteria-based checklists to determine whether or not the insurers are going to pay for the genetic testing. The rules that are generally applied include a comprehensive family history. There is a fear about this test being prohibitively expensive. Michael thinks that insurers have some catching up to do; however, with some focused attention, he thinks this issue will become more important to insurers.

David Fusco asked Michael for an explanation of the value proposition for genetic testing after an ovarian cancer diagnosis. Michael said that this is the only syndromic cancer test that does not have the checklist-based criteria for insurance coverage. One of the reasons it is chosen is because it is achievable without as many hurdles. Michael explained that one benefit is the ability to change a woman’s care plan based on the diagnosis. There is a whole new class of cancer drugs that are specifically targeted to cancers associated with

these genetic changes, as well as additional screenings. The third benefit is the potential to get female family members tested so that they can receive early interventions if there is a positive result.

Alan Kaye asked what Michael is trying to achieve and if he is asking for time, resources, funding, or if this presentation is purely informative. Michael said that the workshop was held two weeks ago, and he became aware of an opportunity to get funding around this type of campaign from the Centers for Disease Control and Prevention (CDC). He believes that a collaboration between the HIE, the Yale Center for Genomic Health, and others who are interested would be great, but there is no specific ask at this time. Allan Hackney added that Michael has described a particular use case, but there are other HIE use cases that could be beneficial. Allan added that within the funding that we have for developing the HIE, we have resources to test the feasibility of some of these use cases and try to promote them to a point where they can be part of the production library.

Dina Berlyn asked if there is a gene that has a mutation, or if there is a specific gene that is the cause of ovarian cancer. Michael explained that there is a change in one of the genes that would predispose somebody to this type of cancer. Michael explained that what was once called a mutation is now called a variation.

Alan Kaye asked how this presentation fits into the current set of priorities and objectives. Alan Kaye is concerned about this topic, as well as artificial intelligence. Alan Kaye does not think we are ready to start tackling these types of use cases and would like to see the HIE direct all of its resources towards the transmission of information between providers and patients, and payers as a secondary level. Alan Kaye said he would be very concerned if this work around genomics would distract any HIE staff or funding. Allan Hackney thanked Alan for his comments and said he thinks there are two reasons why Alan should be less concerned about this topic. One reason is that OHS and DPH have collaborated with Yale to request a very significant amount of grant funding from the National Institute of Health. If this is successful, OHS will be notified in late 2019 and the performance period will extend for five years. The second reason is that the HIE will have a Use Case Factory, which is a process by which ideas are put forward, studied from a feasibility point of view, tested and piloted, and then a decision is made about the production of that use case. The long form gives organizations the opportunity to work on the committee that manages the Use Case Factory. Genomics would fall into this Use Case Factory process and the HIE will have plenty of resources to fund this opportunity and it will not interfere with any of the HIE's objectives. Alan Kaye said that any proposal that is developed on this topic, or any other topic with a futuristic component, should have funds included for any necessary resources, as opposed to using HIE resources. Allan Hackney said that the Use Case Factory activity is funded through the current IAPD and the HIE is able to tap this funding for the exploration of future use cases. Alan Kaye said he would not want to see funding for genomics take away from other, more immediate use cases that are more important to the HIE's goals. Allan Hackney said that the funding for the Use Case Factory is categorically different than the funding that will be used to make connections, or build the identity management, or to get clinical documents moving.

<b>6.</b>	<b>Establishment of the HIE Entity</b>	<b>Office of Health Strategy</b>	<b>1:45 PM</b>
	Allan Hackney introduced the next topic, pertaining to the establishment of the HIE entity. Allan explained that OHS has been working closely with the Office of Policy and Management (OPM) to answer a series of questions relating to the establishment of the HIE entity. The statute that gave rise to the creation of the HIE requires sign-off from the Secretary of OPM on the Articles of Incorporation. Allan expects we will be finished with this process very soon; however, he cannot provide an exact date.		
<b>7.</b>	<b>Development of the HIE Trust Framework</b>	<b>Allan Hackney / Sabina Sitaru</b>	<b>2:05 PM</b>
	Allan Hackney explained that OHS is making progress on the establishment of the trust framework, which is the legal basis by which data will be shared and the principle legal underpinning for how the HIE will operate. Allan introduced Sabina Sitaru, the future Chief Operating Officer of the HIE, who will present a primer on this topic. Allan wants the Council to have a conceptual idea of how this HIE is approaching the trust framework,		

as it is being socialized with stakeholders. Sabina explained that the organizing principle of the trust framework is that the covered entities with relationships in common may share individually identifiable health information. The disclosure must pertain to the covered entity's relationship with the shared patient and sharing must fall under one of the HIPAA permitted purposes of treatment, payment, or healthcare operations (TPO), or as required by law. Sharing can also occur for certain public health purposes.

Sabina explained the steps to legally connect to the HIE entity. The first step would be to execute one of the following agreements: (1) Qualified Data Sharing Organization Agreement (QDSOA); or (2) Simple Data Sharing Organization Agreement (SDSOA); or (3) Terms of Service (ToS). The second step would be to execute Use Case Exhibits (UCEs) to share information. The third step would be to engage in Pilot Activity Exhibit (PAE) process for prototype and exploratory activities. The QDSOA, or long form, allows for participation in the HIE entity's governance model. The SDSOA, or short form, does not allow for participation in the governance model. The ToS is the electronic version of the SDSOA. The UCEs are used to exchange data and are executed to participate in specific use cases, at the discretion of participants. This is designed to be a modular process. Statements of Work (SOWs) would be used to exchange funds and are only executed under either the QDSOA or the SDSOA, but not the ToS. These funds could be used for technical assistance, as an example. Sabina explained the chain of trust. Each organization that signs a QDSOA or SDSOA becomes a Trusted Data-Sharing Organization (TDSO), and thus creates a chain of trust.

Next, Sabina explained the elements of the QDSOA and SDSOA, including definitions, HIPAA business associate terms, contracting and payment, cyber liability insurance, indemnification and liability, basic connection terms and service-level agreement, dispute resolution, and term and termination. The UCEs would become part of the agreements once executed. UCEs include the following: purpose, use case diagrams, definitions, use case details, service interruptions, responsibilities of parties, other terms, and the use case implementation guide link. Sabina provided several examples of UCEs, including continuum of care and consent map (CCCM), encounter notifications, C-CDAs, and more.

Sabina explained the difference between a UCE and a PAE. Once the PAE expires, it is converted into a UCE. The PAEs are a way of testing and validating ideas. Sabina also explained the proposed governance model. When an organization signs the QDSOA, they have the opportunity to serve on the Entity Operation Advisory Committee, which has oversight over issue remediation, among other responsibilities. Sabina explained the steps of the dispute resolution process, which applies for disputes between two TDSOs or between a TDSO and the HIE entity

David Fusco said that the main distinction between the long form and the short form seems to be around governance. David asked if the participants are choosing which form to sign. Sabina said yes, participants choose which form they want to sign. David asked if there is a cap on the number of organizations that can participate in the governance model. Sabina explained that there is not a fixed number of participants who can serve on the governance model. Allan added that there are some additional differences between the long form and short form, such as the cyber liability requirements. Allan said there are responsibilities associated with signing the long form. This model has been used successfully in New Jersey and Michigan. David said that he hopes this model would not prevent the HIE from having the right group of organizations and mixture of viewpoints represented in the governance model.

Sabina said that the graphic on slide 35 nicely explains the differences between the agreements and provides details on HIE vendor agreements. Sabina said that there is a flow to the agreements, and everything is intended to be modular. Sabina presented a proposed structure for the Community Health Center Association of Connecticut (CHCACT). They have been reviewing the draft legal agreements. In this situation, they would sign the QDSOA and have a place in the governance model. Allan Hackney explained that CHCACT is in the process of establishing a data warehouse of clinical data that they can use to deliver various reports that would enable the Federally Qualified Health Centers (FQHCs) to improve outcomes, lower costs, and more.

For this purpose, CHCACT would like to join the HIE for the purposes of exchanging C-CDAs from FQHCs. CHCACT would like to share data back and forth with the FQHCs and also represent the FQHCs on the HIE's governing body. The individual FQHCs would sign the SDSOA so that they can exchange data. However, they would be dependent on CHCACT to represent their interests in the governance model. A similar structure may be used for other associations, and integrated organizations with multiple EHR installations.

Pat Checko asked who the responsible reporting entity within this model will be and who will be responsible for data quality and liability. Pat also asked for the difference between the Board and the Operation Committee. Allan Hackney said that the point of entry for the data will be both CHCACT and the FQHCs, who will both have bi-directional connections with the HIE for each UCE that has been executed. Allan added that the quality of the data is the responsibility of the healthcare organization that has an EHR system and the HIE expects to have the capability to help cleanse the data. CHCACT wants to take advantage of the data cleansing services and identity management to help improve their own data warehouse. The HIE will have a role in terms of monitoring data quality and helping organizations to understand where their data quality can be improved. Allan said that in terms of liability, the framework speaks to a shared liability for all the TDSOs who rely on the data that is flowing for clinical or analytical decisions. When there are issues related to this, it is the governance framework that takes over and resolves this with participants. Participants will still have the ability to sue the HIE and the HIE will carry its own insurance coverages. The member-to-member liability is a shared model. Allan said that in terms of the governance model, the Operation Committee will oversee all five listed committees; however the Board is the ultimate authority with respect to resolving issues that cannot be resolved within the presented framework.

David Fusco asked if this process will yield the right representation, or if the HIE needs to have a target representation in order to get the right balance. Allan Hackney said that he thinks the HIE is likely to encourage certain organizations to pursue the long form in order to get the right composition. This model has been successful in New Jersey and Michigan. Allan said the HIE will try to guide people to make the right decision for their organization. Tim Pletcher of Velatura was asked by Allan to provide his experiences. Tim said that Michigan has a similar model. Being part of the Operation Committee comes with responsibilities. There is nothing that prevents the entity's Board from assigning other organizations to the Operation Committee. Tim said that most of the organizations sign the short form. A lot of groups feel comfortable with the representation they receive from larger organizations or associations, such as a hospital association.

Pat Checko said that, based on her experience on the design group, it appears that the organization would be the node and she is not sure how this kind of model would work. Pat said that CSMS has created their own HIE and they intend to serve as the reporting device for the providers they represent and asked if this would look the same as the model being proposed. Tim Pletcher said that this will continue to evolve – this is a framework and not a solution. Tim said it would be very appropriate for all of the members of CSMS' HIE to sign the short form, and then have the legal entity (CSMS) sign the long form. However, this would not work for all of CSMS' members, such as certain specialists.

Alan Kaye asked if we are talking about the "Data Stewardship and Governance" box on the governance model's organizational diagram (slide 33) and if this is where the entity will fit. Allan Hackney said that this is correct. Alan Kaye then asked if there will be a review or veto process for who can serve on the Operation Committee as he is concerned about having too many participants. Allan Hackney said that ultimately the Board of Directors have veto power; however the question is when the Board should exercise this ability. When the HIE was developing this framework, we discussed the instances in New Jersey and Michigan when the Board used this veto power. Typically, this was when some of the for-profit service providers wanted to be part of the Operation Committee, which could be construed as a conflict of interest. Allan thinks there are other circumstances where the Board could have judgement on this. Alan Kaye thinks we may be setting ourselves up for some unintended consequences. Tim Pletcher said that you want to start with the assumption that people will behave properly. We want as many people as possible to legally connect with the

HIE, and then want people to enter into specific data-sharing use cases. At some point the HIE will produce reports for everyone who is connected to the HIE, and those who are participating in use cases. It will be clear if there are people who are just sitting on the Operation Committee and not participating in the use cases. At this point, a participant could bring this discussion to the issue remediation process. David Fusco clarified that his questions were not suggesting bad behaviors. His questions were suggesting that we should find the right process to yield the right distribution of stakeholder representation.

Pat Charmel said that the CHCACT structure that was described makes a lot of sense, but he is wondering if this sets a precedent or makes commitments. Pat said there may be other organizations in a similar situation as CHCACT, however they may have members that want to sit on the Operations Committee. Pat asked if the HIE has made certain representations to these groups about the process and who can serve on the Operations Committee. Allan Hackney said that the HIE has not made these representations. The HIE's view is that they want to optimize the optionality and the structure should serve the best interests of the TDSOs.

Bruce Metz thanked Allan and Sabina for the presentation and their work. Bruce said that the idea here is for nationwide interoperability. Bruce said that the 21<sup>st</sup> Century Cures Act requires ONC to develop the Trusted Exchange Framework and Common Agreement (TEFCA), which may still be in the late stages of draft form. Bruce asked if there is any thinking as to why we would stay with the New Jersey and Michigan model when the national interoperability standard will be coming out in the near future. Allan Hackney said that when Connecticut approached the idea of developing this trust framework, there was a design group that developed recommendations, one of which was to align with TEFCA. It was on the basis of the original TEFCA draft that the HIE reconciled the work from Michigan and New Jersey to ensure that the framework would be harmonized with the principles of TEFCA. Allan said that over time, ONC closed the comment period and are in the process of producing the next version of TEFCA. In the meantime, ONC has come out with two notices of proposed rulemaking, one of which addressed the information blocking portion of 21<sup>st</sup> Century Cures Act and the other addressed certain data sharing needs of CMS. Allan said that he thinks the framework is still in alignment with the two proposed rules and is well-positioned for where the federal government is heading. Dina Berlyn said that ONC has been very aware of what Connecticut has been doing, including the state's efforts to address information blocking. Dina does not think there is a conflict here.

Ted Doolittle asked if the long form carries the opportunity to participate in the governance model, or if it requires participation. Allan Hackney said that under this model, if you sign any agreement, all you have done is legally connect your organization to their HIE. An organization starts participating in data sharing by signing UCEs or participating in the exchange of funds by signing SOWs. If an organization signs the long form, the organization has the opportunity to participate in the governance model, even without signing a UCE.

Allan Hackney then explained an example of the modularized structure. The HIE is agnostic to whether an organization signs the long form or the short form. The modular framework allows any combination of participation in data sharing use cases, SOWs, or HIE governance. Allan also presented an example structure for other networks, such as CSMS's CT HealthLink. Allan expects that CSMS will want to sign the long form. Other networks will connect via the long form or the short form and will manage local data use agreements (DUAs) for their own direct connections. The other networks will participate in use cases the same way as every other participant. Allan also presented an example structure for state agencies. There will be a state version of both the long form and the short form for a number of reasons. For one, the issues around liability are different, as states enjoy sovereign immunity, and this must be respected. Also, states have needs for data sharing which transcend the ordinary TPO allowances under HIPAA. Most state agencies have reasons to gain access to identifiable information for the purposes of public health or the delivery of healthcare services. The UCEs and the SOWs will be identical for state agencies as they are for other organizations. By engaging each agency in a use case or SOW basis, we now have the ability to share certain pieces of data amongst state agencies, and between state agencies and the rest of the healthcare sector. This is very powerful. From Allan's point of view, this will change the landscape.

Next, Allan presented a timeline for the trust framework. The HIE is beginning to socialize the framework with various organizations and are scheduling meetings with state agencies. At this point, the HIE is looking for feedback – they are not asking people to sign the agreement. The HIE wants to get to an agreement that makes sense for Connecticut. When we get to May or June, when the IAPD funding is approved and the HIE is up and running, then the HIE will be going to ask organizations to sign the agreements.

Mark Raymond thanked Allan and said that he understands that the enabling structures that are being put in place by these documents are critical but is wondering if the framework includes the concepts of individual consent and tracking consent across the framework. Allan Hackney said that the organizing principle focuses on the HIPAA TPO allowances and that this framework is enabling the data sharing associated with this. Allan said that when you get into the specific use cases, there are frequently reasons why you would need individual consent, such as for the exchange of behavioral health information. The concept is that these consent rules would be detailed in the behavioral health UCE. The use cases will address these specific situations. Allan added that there is a Consent Policy Design Group which is about to get started that will review these issues in more detail.

Tekisha Everette thanked Allan and Sabina for the presentation. Tekisha said that she is concerned that the Operation Committee will be a big, unruly group that is not well designed. Tekisha also asked about the name of the HIE entity. Allan Hackney said that the HIE entity needs to be incorporated and the reference in the slides is only the current legal name. Allan said that another survey is about to be launched, which will create a new name under which the entity will do business. Tekisha added that the acronym of “HIS” could be problematic as a gender-related acronym.

Allan thanked the Council for the thoughtful discussion. Allan said that anybody who represents an organization that wants to be involved in the process of refining the framework should send him an email. It has been Allan’s experience that getting the trust framework right is the most important part of the process.

<b>8.</b>	<b>Wrap up and Meeting Adjournment</b>	<b>Allan Hackney</b>	<b>2:55 PM</b>
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Kate Hayden, of UConn Health, said that OHS is putting on a medication reconciliation hackathon. They are looking for clinical and technical attendees to register. The hackathon will take place on April 5 and 6. Anybody who is interested in more details can reach out to Kate for more details.

Allan Hackney asked for a motion to adjourn. The motion was approved without objections or abstentions.

**Upcoming Meeting Schedule:** April 18, 2019, May 17, 2019; June 20, 2019

**Meeting information is located at:** <https://portal.ct.gov/OHS/Services/Health-Information-Technology>