OHS CONNECTICUT Office of Health Strategy

Health Information Technology Advisory Council
DRAFT Meeting Minutes

Meeting Date	Meeting Time	Location
November 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	Ted Doolittle, OHA	X	Robert Blundo, AHCT	
Joseph Quaranta (Co-Chair)	X	Mark Schaefer, SIM	X	Lisa Stump	X
Joe Stanford, DSS	X	Bruce Metz, UCHC CIO	X	Patrick Charmel	X
Madelyn Straub, DMHAS	X	Robert Rioux		Alan Kaye, MD	X
Cindy Butterfield, DCF	X	David Fusco		Dina Berlyn	X
Cheryl Cepelak, DOC	X	Nicolangelo Scibelli	X	Tekisha Everette	
Vanessa Hinton, DPH	X	Patricia Checko	X	Patrick Troy, MD	
Dennis C. Mitchell, DDS	X	Robert Tessier		Stacy Beck	X
Mark Raymond, CIO	X	William Petit, MD	X		
Sandra Czunas, OSC	X	Jeanette DeJesus	X		
Supporting Leadership					
Victoria Veltri, OHS		Alan Fontes, UCONN AIMS	X	Michael Matthews, CedarBridge	X
Sean Fogarty, OHS	X	Tom Agresta, MD, UConn Health		Sheetal Shah, CedarBridge	X
Adrian Texidor, OHS	X	Kate Hayden, UConn		Carol Robinson, CedarBridge	X
Tina Kumar, OHS	X			Terry Bequette, CedarBridge	X

Minutes

	Topic	Responsible Party	Time
1.	**Welcome and Call to Order**	**Allan Hackney**	**1:00 PM**
	Allan Hackney welcomed the Health IT Advisory Council members and provided an overview of the agenda. Allan introduced and welcomed a new Health IT Advisory Council member, Madelyn Straub. Madelyn is the Director of Health Information Technology at The Department of Mental Health and Addiction Services (DHMAS).		
2.	**Public Comment**	**Attendees**	**1:05 PM**
	There was no public comment.		
3.	**Review and Approval of Minutes from October 17, 2019**	**Council Members**	**1:10 PM**
	Allan Hackney asked for a motion to approve the October 17, 2019 meeting minutes. Nicolangelo Scibelli made a motion. Patricia Checko seconded the motion. All in favor. **The motion passed to approve the October 17 meeting minutes.**		
4.	**Review and Discuss the Consent Design Group Guiding Principles**	**Michael Matthews, CedarBridge Consent Design Group Members**	**1:15 PM**

Michael Matthews reviewed the *Final Report and Recommendations of the Consent Policy Design Group.* The Final Report can be found here: https://portal.ct.gov/-/media/OHS/Health-IT-Advisory-Council/Reports/OHS_Consent_DG_Final_Report.pdf.

The presentation can be referred to here: https://portal.ct.gov/-/media/OHS/Health-IT-Advisory-Council/Presentations/OHS_HIT_AdvisoryCouncil_Mtg_Presentation_112119.pdf

Michael Matthews shared that the first three guiding principles (pg. 10) have to do with the ability of consumers to be informed about any and all consent sharing policies and practices, toolsets, etc.

Refer to the Consent Design Group's Guiding Principle recommendations #1-18 on pages 10-15 here: https://portal.ct.gov/-/media/OHS/Health-IT-Advisory-Council/Presentations/OHS_HIT_AdvisoryCouncil_Mtg_Presentation_112119.pdf

Recommendation 1: Basic foundational guiding principle of being providing clear and detailed about health information sharing choices under applicable State and Federal law.

Michael commented that throughout the entire course of the deliberations of the Consent Design Group, they had a strong suspicion that coming up with complete anonymity on every single issue on something that is complex, and a nuance as a consent might not be a realistic expectation. As a result, the asterisks (*) in document following some of the recommendations indicated that there were additional or different opinions from Consent Design Group individuals that they wanted to express.

(Refer to pg. 16) Out of the 18 guiding principles, four of the guiding principles had additional considerations offered by individuals from the Consent Design Group. The 18 guiding principles had a majority approval of the Design Group. Alan Kaye asked if these were the recommendations of the group, or if they were individual comments? Michael Matthews clarified that slide 16 are individuals' comments, the recommendations themselves are from the group. William Petit commented that in referring to page 16, guiding principle 1, that biggest concern from a consumer perspective is looking at the "opt-out," vs. "opt-in" concept. Rep. Petit added that this is a very complex area in sharing a lot of private and personal information. It seems like "opting in" after getting the information of what's available makes more sense from a consumer point of view from a privacy perspective. He understands that from a researcher point of view, that the "opt-in" would make more sense.
Michael Matthews commented that this is an important consideration and discussion of the Design Group. As the health information exchange grows more diverse, people are beginning to move past the binary ""opt-in"" and "opt-out". If the term "opt-in" and "opt-out" is used, then this would be a policy. This is what was set aside for this group. The guiding principles would apply to any and all of the future use cases.

Patricia Checko added this was a very intense discussion of the Design Group, and one of the great things about the group that no matter where we are in spectrum of opinion, we all respect each other and try to come through some sense of consensus. Pat mentioned at the last meeting, this turned out not to be as simple as "opt-in" and "opt-out". The process came down to each use case. The initial challenge with the group was thinking about the initial establishment or mapping of identifying the providers for the patient.

Michael continued to review the Guiding Principles. Guiding Principle recommendations 2 and 3 have to do with providing educational resources and a toolkit. A few aspects to this that are important is having a place the consumer could refer to that includes basic information and additional information. The second aspect is making sure the information is available to all.
Mark Raymond asked if there was any consideration to say we would like most consumers empowered, or patient privacy approach applied to each one of the use cases as they are developed. So that in some ways, we've attempted to guide the future specific policies as they come out with a desire to be the most patient empowered. This is around being provided the most restrictive choice to help them to say in all things being equal we would provide an "opt-in", in certain circumstances that look like "x" we would advocate an "opt-out".
Michael believes Mark's point is addressed in recommendation 18.

Michael continued to review the recommendations.

Mark commented that later on in recommendation 18, we talk about who looks at each one. In recommendation 18 it will clarify who it is. This looks more generic and reads, "appropriate subject matter to review." What does this mean? Is it the patient or provider?

***A modification to recommendation 18 should be made to the consent policy to clarify who it is rather than a random subject matter expert.**

Lisa Stump commented that (if) these are guiding principles which all have purposes, it implies they are recommendations under, which we should construct our process going forward and through the work of the HIE, these will then be translated as appropriate into policies and procedures for participation. But these are not going to be what regulate or require participants to whether a provider or otherwise-this is the first step of what will ultimately be putting more accountability and rigor of how the Health Information Exchange is operated.
Michael commented that there would be consent policy developed and implemented (as use cases are developed). Any policy around consent then should be tested against these guiding principles. If there's an exception that it meets 17 out of the 18 principles, what is the one that it doesn't conform to? (maybe justification, not absolute) these would be the guidelines upon the consent policy would be developed.

Michael continued to recommendation #5 that has impact behind the Health Information Exchange in Notices of Privacy Practices (NPP). Michael recognized Rachel Rudnick, Chief Privacy Officer (UConn Health) who has been very helpful on this topic and across the board. The idea here is that if people are participating in the both the health information exchange, and Health Information Alliance of CT, and potentially others, to inform their patients and consumers in health information exchange.

Recommendation #6 is regarding provider burden that has nationally become a term of art. This is a priority for the Office of the National Coordinator for Health Information Technology (ONC), and a driver for The Office of Health Strategy (OHS) and aspirations for how the HIE would work. It is unrealistic for a provider or health system to implement this guiding principle, let's be mindful of the impact of how the consent policies are rolled out without providing undue burden to providers.
Patricia Checko added that this is regarding the important caveat for the consumer's consent.

Recommendation #7 is about how information for consent policy changes are provided.
The initial consent policy comes into play. Making sure whatever consent was exercised two years ago, that if the policy changes to make sure they are aware of change. Mechanisms to inform the consumers.

Mark Raymond commented on the topic of education and awareness, most important part of communication is that people actually understand what we are trying to communicate in first place. There appears to ascribe to principles and communicate outwards, but how are we tracking if people are getting it or understanding? Is there a mechanism that people can understand what is communicated, i.e. survey? Michael responded that the principles are around making sure people understanding what is communicated. Nicolangelo Scibelli added that it's a great idea to do a survey to see what people understand in terms of informed consent; always asking patients if they know what they signed, and attempts are made. It would be great research to see if people actually understand what is signed.
***flagged for consideration, add 19th Guiding Principle? Ex. Some kind of evaluating mechanism to make sure patients understanding the policies.**

Patricia Checko added that as we think about why we came up with these principles, the governance body is the health information alliance. Pat questioned whose burden would it be to do the survey? The education is going to come out of the alliance, and OHS.

Mark Raymond commented that this is fabulous work and agrees with the idea of checking in with the patient-whatever it may be and not just informing but measuring in some way that they understand.

Recommendation #8 is regarding the mechanisms, including paper based and digital tools, for expressing consent policy preferences should be user-friendly and easily accessible.
Mark Raymond asked if there is a preference for digital? Prefer to have people interact digitally.
Patricia Checko insisted that paper is available for people who have no access to the internet.

Recommendation #9 states that policies should be clear on what happens when a patient revokes their consent, including what happens with patient data and their previously expressed consent-needs to be expressed clearly. Lisa Stump commented that if we try to link all the recommendations together, if consent happens uniquely around an individual use case. If, I revoked my consent if I've consented at the time for an individual use case, are we suggesting we might need to consider pulling my data out of a specific use case that I consented to? (If we are truly adopting use case by use case). Michael answered that this does not express any preference on what that policy is and whether it be use case by use case. This guiding principle says that if the patient revokes what they previously consented to, they need to understand what happens at that point.

Recommendation #10 speaks to whichever consent policies are adopted and implemented that everyone who is part of the information sharing eco system, including vendors who are bound by Business Associate Agreements (BAAs) needs to abide by the same set of rules. Whatever policies are they need to be implemented regardless of who the contractors are. Mark Raymond commented

that this implies there is a different standard to those entities (BAAs), it should explicitly state it should apply to everyone.
Michael Matthews added that this ensures that this applies to all who participate. All of these recommendations are applicable to covered entities, governed entities, business entities and sub-contractors.

Lisa Stump said she is confused by this statement and that all exchanging health data under standards like MU; we are exchanging data in a way that's HIPAA compliant. She believes this is starting to overstep in trying to set standards for providers and organizations that are already providing data. Nicolangelo does not object to those comments and agree with what Lisa just said. Nicolangelo potentially thinks it would be overreach and would be fine with it being modified.
Pat commented that she also does not have an issue with this.
Susan Israel commented that she understands what people are saying but suggested we could add covered entities to the first part. Referring to the last sentence, "*and prohibit use or disclosure of patient information (including de-identified, anonymized or pseudonymized data) for any undisclosed purposes without express consent from the patient.*" Susan commented that this line is different, because a lot of data is exchanged by applied consent just by agreeing to treatment. The notices of HIPPA forms are just signed to acknowledge what the patient read, but not agreeing to consent. The last sentence needs to be discussed differently.

Carol Robinson commented that she understands what Susan is saying, part of the intent on this is the lack of clarity. The BAAs would need to have protections on the data with third party apps. Secondly, in a federated HIE network, having different policies becomes untenable, that is what the intent was.

Lisa Stump added that it's a very long sentence so breaking down the components, to ensure BAA exists wherever data exchange occurs, then say that. If it's meant to be with HIA and the way its worded, anyone providing health care and doing digital tools – it gives her pause on how far reaching it will be. If we cleanly define the scope.

Michael Matthews said we can modify this down to something that HIA should require of the and the BAA. Do people believe that adding the preamble, "this applies to the covered entities and non-covered entities part of HIA," would be helpful?

Lisa Stump asked if we are suggesting an individual provider group? If we have private health care facilities actively involved in research and are relying on the use of de-identified data in many ways, we are saying that should include consent from the patient. How would we hold the organizations accountable to do that?
Michael agrees that this is a good point. This is a guiding principle, not policy.

Alan Kaye commented he is having a little bit of trouble with the recommendations. He noted they are guiding principles and suggestions for policies. He thinks that Lisa and Joe Q comments bare on this; not sure that recommendations need to be in this when Recommendation 11, should be in broad policy considerations, guiding principles; should we stick to just principles. Does the patient

have to see every BAA and not sure if it is workable? If we worry about providers, this could turn into chaos for providers. We should strike recommendation 11.

Susan Israel added a comment I think that a lot of thought went behind it. If recommendation 10 is cut, then it would be in additional considerations – the issue of what patients understands is what we're doing with the data and any changes to that; not sure what rules are for HIPAA. You may be able to sell de-identified data according to HIPAA; and not sure if the data sold by APCD, is it written in for example, that you can sell it. Susan added she is not sure – at least second part of sentence be left somewhere so people who make policies think about everything.

Alan Kaye asked for clarification for "every patient should opt-in and know who BAA are," would every encounter have to know who the business associated are?

Susan Israel said this is a good point, and it wasn't clear if everything was going to require a consent. But allowing people to have a global "opt-out" and an explanation of what data would be sent where; and what's identified or not. Susan suggested to keeping the dialogue open and then take into consideration about the practicality of it.

Dina Berlyn asked what is an undisclosed purpose? Would they not do an additional consent? If it was something, we're looking to see? For example, if vaccination rate drops off when people live in rural areas…." Or is this for when we're requesting data and not explaining what they are going to use the data for? Michael responded that the idea here is that BAA can't use that access to information and use it for unpermitted purpose. Dina commented that it's not problematic; it's a narrower of scope. It's an important 2 words: **undisclosed purpose.** Michael suggested a check-in with group, flag for follow up and go through all of them or wrestle.

Carol Robinson suggested the council review all of the recommendations, and if there are others to consider rewording then we can go back to them in December.

Michael Matthews did a check-in with the council members whether they should flag for follow up and go through all of the recommendations or wrestle them one at a time.

Allan Hackney opted for the suggestion and noted three modifications. Allan advised to get through the ones people agree to, and then come back to the ones to make adjustments to.

Michael continued to Guiding principle #11. This was one that Rachel Rudnick had good thoughts on, Rachel thought it would be good to have; should require safeguards for patient information and be consistent with responsible stewardship, protection, authorization. Alan Kaye agreed that this is a guiding principle.

Guiding Principle 16 recommended that consent policies should require that patients have ample opportunity to review educational material before making a consent decision. Michael added time should be taken for someone to have an understanding and what they are asked.

Guiding principle 17 recommended Consent policies should require a consent decision is not used for discriminatory purposes or as condition for receiving medical treatment.
Joe Quaranta agrees with this intent; but explained there could be a situation where a clinician does not have access because of a consent decision chosen by a patient. Clinician could say if I don't have xyz information. For example, if the patient says, "I do not want to share my medication list" and agrees with this intent, but if a patient does not want to share, the provider cannot participate in an appropriate clinician relationship and maintain information. He gets that it should not be punitive, but it could be directly related to patient care.

Alan Kaye commented that similar to Joe's comment, that another unintended consequence is that we don't want to restrict care. He believes the intent is to require or facilitate as many providers in the HIA in order to provide better care to constituents. The fact that many of us have converted to health records, not participating in this may conflict. It is making it easy on the providers and this could create issues with health care information.

Michael Matthews added that some of you may be aware of NPRM for information blocking, and that one of the examples ONC uses is that health system requires consent for treatment. One idea could be to add a "period" after discriminatory purposes. Joe Quaranta suggested put period or add a modifier.

Lisa Stump agreed to adding a period after the discriminatory purposes. She added that we started the conversation a year or two ago if HIE was noun or verb; at this point is unclear if we are talking about the broad topic of HIE information. Tried to be vocal about exchanging information today is happening or talking about establishment of statewide HIA/HIE and use of data for specific use cases. She agrees that it is very well intended concepts/principles, but not sure there is full clarity around the boundaries of those statements are meant to address.

Michael Matthews commented that he understands the question and guiding principles 18 may shed light on parameters and context for these that are related to consent policy framework for HIA; as statewide HIE. We talked about possibility using this for broader legislation, regulation, statuary development; but that was outside scope of the recommendations where we ended up.

Alan Kaye commented that he sees where this may cause concern for other individuals/organizations; research purposes. If we are talking about individual use cases; but on other hand if we interpret use case for purpose of regulation. Is the information shared among providers? Or is there an additional level of concern when payers or regulators/legislators have access to the information? This can cause a different level of concern-for example for health policy or research concerns when the information is available.

Michael Matthews suggested we can consider those to be questions applicable to any particular use case.

Dina Berlyn added that (along lines of Lisa's comment), whether patient opts in or out, the record will exist.

They are going to be created, the big part of the HIE is whether the patient have control over them. Michael added that it is "control over them and the transaction of the medical records across the HIE infrastructure." Dina said there's going to be transactions across a variety of things other than the HIE.
Even if you "opt-out" of the HIE the insurance and hospital are going to be sending information back and forth. What do you get by opting out? I know you have to have ability to do that It should be made clear-this is just for the HIE, it doesn't stop their entity from sending your records as they have always done.

Michael said that we are in agreement will add a period for now.

Recommendation 18 is about process. How are the consent policies going to be drafted and reviewed and ultimately implemented; preamble with eight sub principles – transparency and stakeholder input are foundational. Drafting of the policies would be created by this group; sent to OHS; and once you pass that review, it would be referred to HIA for implementation. Refer to page 15. *

William Petit suggested that if you want public buy in, we should host a public hearing or informational forum to involve the public. He advised to advertise it on Facebook, Instagram, Twitter to communicate with people, since very few people go to the state website and rely heavily on social media.

Michael asked Rep. Petit to elaborate on this idea. Rep. Petit added, we can use the first 30 minutes of a council meeting to do this. It depends upon the advertising of the event-if you want few people to show, do a terrible job advertising. It may be better as a stand-alone until you have an idea of who may show up; if only 5 people show up with certain amount of time to speak, it's a short hearing. This could be a way to articulate it to public so that people understand, and then are able to express their concerns on it.

Allan Hackney commented that this is a very good suggestion and that the whole point is to solicit the public input into this.

Carol Robinson added that she has seen this in other states. This is another area where we could come back with a suggestion on how to structure the ability to notify consumers across the state of actions that are being taken and giving them opportunity to comment electronically; website and learn more and have a voice in this and proposal for that as well.

Pat Checko said that she is very happy with recommendation 18 and concerns over self-governing group; but that it is important to read the comments of person who is not necessarily in agreement. Someone wanted to go through regulatory process for every use case. Want to draw attention for every use case; while we want process to be transparent and have opportunity to talk about it and why it's a good thing for consumer to have it happen, but don't want to be in a position that they can't even do patient mapping. There were some people who said legislation. Think it's critical for consumer and transparent but not to make it so onerous in an appropriate amount of time.

***Modify Recommendations 18h, and 10.**

Michael Matthews commented that it would be easy enough to add principles based on Mark Raymond's comments. The mechanisms should have in fact understanding information sharing stories and the HIA would that.

Alan Kaye commented that in recommendation 4, thought 18 would be different, doesn't see anything that changes suggested in 4. Well into this process, we had meeting and phone calls with people from other states that had done HIE. It was almost universal – stated obliquely –that the opt-in process is much cumbersome than opt-out process. At the time, we were going to try to go for an opt-out methodology. Now, each use case – but we seem to be taken to the point where the HIE will fail; information blocking and addressing these things. They will die by micromanaging trying to reinvent this; I would reject the use of them.

Susan Israel responded that she dissented on this stuff, she wanted to start with simple opt-out and develop things after that. She suggested to start with one principle that patient can control who sees their data.

Alan Kaye asked if we can the "opt-out" as a default?

Carol Robinson responded that to give people context we want to make sure health system/providers understand this – Dr. Israel's view is to have patients "opt-out" of having your data sent to the HIE vs. opting out of your data being ever shared from the HIE. They are different from the technical point of view and the issue of opt-out broke down in the consent design group process. It really matters to the health system/provider offices to technically do that. They need to make sure we are clear on understanding.

Lisa Stump added that if the patient opt-outs the burden is not on provider or the hospital; it's up to HIA to block it out on receiving end because no provider organization will be able to adjudicate individual patient that.

Susan Israel commented that she didn't understand what Carol explained about the two different ways, is advocated wants a complete open discussion and how it all fits in; the public aren't aware. Susan would also like to ask Pat about concept about identifying data and association with providers. She believes this is another issue that is addressed.

Carol Robinson responded to Susan that that if technology blocks data from being stored from the HIE record; what I understood from the conversations your concern was whether the vendor would see the information to be able to block it. That was something we found to be probably not be feasible from an opt-out provider level; because it all gets pushed. There needs to be a flag and vendor who needs to say we are blocking it.
Lisa Stump asked if the vendor will be able to see it? Will someone see my data in course of opting out?

Michael Matthews said that the past five minutes of this discussion was why we ended up with guiding principles rather than consent policies. Some of these definitions and specificity are a technical approach; those will be known in exquisite detail and get into the "what about" very quickly; until all of those answers are developed; for this specific use case – here is an appropriate consent policy. If we didn't have that; don't know if there are 30 different. There will be a consent policy review; and may be treatment review for these cases.

Michael continued to review the Additional Considerations in the final report. The additional considerations are not for the council's approval or disapproval – they are comments for those who are developing policies. This ties back in 4 different places.

Next Steps
Michael said that there will be some tweaking on some of the principles and will be keeping a close eye on final information blocking rule. Then as defined by guiding principle 18, they will begin; there is a sizeable amount of money in the IAPD to have a consent management tool and fully integrated as part of HIE. That is being built out, there may be simpler mechanism for consumer to indicate their preferences and take a look at that as well.

Allan Hackney and Joe Quaranta agreed to conclude that we will table the idea of any council action today, in lieu of cleaning up recommendations 4,10,17,18 plus a potential new one and bring that back for the council.

Pat Checko commented that she noticed that we stayed away from establishing straightforward opt-in or opt-out in any of these guidelines; we were first charged trying to develop consent policy around patient mapping. There was a tremendous amount of discussion. This is to make things better for the consumer, greater teamwork, and there needs to be as much education for the consumer as to why this is good for them. HIPAA allows data; guidelines should not consider opt-in/opt-out. If you don't like 4, we can look at it but don't want to try to answer the opt-in/opt-out question.

Alan Kaye asked if HIPAA already addressed the sharing of information? So doesn't HIPAA give ability to share; so if we look at individual use cases outside of that shouldn't we make it – so that sharing with payers, regulators is what you opt-in or opt-out; don't think it's in patient's interest to opt-out of data sharing with providers unless they have a specific reason of being opposed to it. We are not doing what we are charged to do – meaning providers and people making regulations.

Allan Hackney said that being mindful of the time, we will go back to the advisors in December. Allan added that the advisors made great progress in this very robust discussion, since April. This is a thing people are passionate about.

5.	**Council action: Accept, Reject or Modify Consent DG Recommendations**	**Council Members**	**2:10 PM**
	This is tabled to the December 19, 2019 Council Meeting.		

6.	**Review and Discussion of Proposed Milestones for HIE Deployment**	**Allan Hackney**	**2:15 PM**
	Review Key Early Milestones to Operations with respect to the establishment of the Health Information Alliance, Inc. Presentation on page 19.		
7.	**Announcements and General Discussion**	**Allan Hackney, Council Members**	**2:40 PM**
	Allan announced that he is distressed to report that Bruce Metz is leaving the State to begin a new adventure in Chicago. Allan congratulated Bruce on this exciting and terrific opportunity and that he will kill it out there. Bruce has spent a lot of time outside the room and working on HIE issues, and a very active member of the Medication Reconciliation and Polypharmacy Committee. Bruce thanked everyone for the acknowledgment and is grateful to be on the Council, and during his time he has been apart of very robust discussions which he will miss.		
6.	**Wrap up and Meeting Adjournment**	**Allan Hackney**	**2:30 PM**
	Allan asked for a motion to adjourn the meeting. Mark Raymond made a motion to adjourn, all in favor. The meeting adjourned at 3:00 pm.		

Upcoming Meeting Schedule: December 19, 2019

Meeting information is located at: https://portal.ct.gov/OHS/HIT-Work-Groups/Health-IT-Advisory-Council