

Consumer Advisory Council

Meeting Minutes

September 15th, 2020

Meeting Date	Meeting Time	Location
September 15 th , 2020	3:30 – 5:30 p.m.	Zoom Meeting

Participant Name and Attendance

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Jeffrey G. Beadle	X	Christiane Pimentel	X	Adrienne Benjamin	X
Alan Coker	X	SB Chatterjee	X	Peggy Lampkin	
Robert Krzys	X	Soneprasith Phrommavanh	X	Andre L. McGuire	X
Velandy Manohar	X	Taylor Edelman	X	Daniel C. Ogbonna	
Terry Nowakowski	X	Ann R. Smith	X		
Others Present					
Terry Gerratana (OHS)		Sean Fogarty (OHS)		Ormand Clarke (OHS)	
Leslie Greer (OHS)		Lindsey Donston (OHS)		Tekisha Dwan Everette (HES)	
Tina Kumar (OHS)		Laura Morris (OHS)		Dashni Sathasivam (HES)	

Meeting Information is located at: <https://portal.ct.gov/OHS/SIM-Work-Groups/Consumer-Advisory-Board>

	Agenda	Responsible Person(s)
1.	Welcome	Terry Nowakowski
	Call to Order The scheduled meeting of the Consumer Advisory Council (CAC) was held on Tuesday, September 15 th via zoom. The meeting convened at 3:31 p.m. Terry Nowakowski chaired the meeting.	
2.	Public Comment	Terry Nowakowski
	There was no public comment.	
3.	Approve July 14th, 2020 Meeting Summary	Terry Nowakowski
	The motion was made by Terry Nowakowski and seconded by SB Chatterjee to approve the minutes of the Consumer Advisory Council meeting of June 9th, 2020. Motion carried.	
4.	Presentation and Feedback session: HIE consent policy design	Tekisha Dwan Everette, HES
	<ul style="list-style-type: none"> • Dr. Tekisha Dwan Everette, Executive Director of Health Equity Solutions, presented and led a discussion about the Connecticut Health Information Exchange (Connie) The purpose of the session was to introduce the CAC to Connie and the consent process. OHS asked that the first listening session would engage the CAC in order to gain their feedback on the first run of this presentation to help build out and refine the presentation going forward as it is presented to consumer groups. The CAC was also engaged to help inform which groups should be contacted for future listening sessions and for guidance on how to best disseminate the information in subsequent sessions. • Alan Coker asked if the EPIC informatics system was going to be main provider of information? • Tekisha Dwan Everette responded that EPIC is an electronic health that is used in most hospitals in CT. She noted that Connie is different than EPIC because while EPIC can much more easily 	

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share information with other EPIC systems, Connie is accessible to providers across different health organizations.

- Terry Gerratana and Velandy Manohar provided clarification on slide 14 HIPPA and CT Law. Ann Smith appreciated the additional clarification as the text in that slide needed to be revised.
- Adrienne Benjamin commented that she hopes the actual notes and charts of psychotherapy sessions are protected. She asked if there were exceptions for emergencies (child abuse, suicidal or homicidal threats?)
- Terry Gerratana asked Adrienne Benjamin if notes and charts are shared now.
- Adrienne Benjamin responded that she fights hard against sharing an individual's psychotherapy notes, but rather just a narrative if needed for a court order or other reason as there is a lot of information in the records that are private and not related to the matter at hand.
- Sean Fogarty responded that psychotherapy notes and charts are protected and may even be designed to have a greater level of protection. Also, these providers would have exceptions to HIPPA if there were emergencies and there are guidelines dictating these exceptions of when and how PHI data can be shared without consent to prevent harm.
- Andre McGuire asked who determines public interest or matter required by law?
- Tekisha Dwan Everette responded that this is usually a government decision led by a major issue as a public health threat, (like COVID-19) that might be then deemed public interest.
- Terry Gerratana commented that this was a good point to follow up on.
- Ann Smith asked what level of access does the Health Information Alliance have to PHI? She also asked how Connie interplays with federal law for substance use disorder records – 42 CRF Part 2. She noted that federal law has always been more strict than other laws. She is interested in how Connie addresses this issue.
- Terry Gerratana agreed that federal laws would be followed.
- Velandy Manohar mentioned the complex interaction with a child's age, and parental consent as it pertains to children's records. He asked if Connie had a strategy to address this. He also was curious if HIV/AIDs testing and results are similarly protected?
- Alan Coker asked if Medicaid ID information protected. If a person has a personal care assistant (PCA), when they clock in, the client's Medicaid ID flashes on the screen. Is information like this confidential and considered protected health information as this is identifying information?
- Tekisha Dwan Everette explained how Connie uses information to identify patients. She explained that Connie uses basic identifying information to create a best record for each person that is unique and can be shared across health organizations.
- Tekisha Dwan Everette highlighted how she will bring Alan Coker's question to OHS to discuss: How at the level of a personal care attendant or assistant, if a PCA would be able to access and utilize Connie to understand how and if the Medicaid ID or other personal information would be protected.
- Adrienne Benjamin asked about a public health circumstances specific to vaccination. For example, with schools not wanting to release which schools had the highest no-vaccination rate. She feels that this is important because vaccination is in the interest of public health.

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- Tekisha Dwan Everette agreed this was important and information sharing is happening at the school-level information, but not sharing data at the personal, individual level. Given that this is a controversial issue.
- Sean Fogarty added that because this is a delicate issue, Connie is carefully exploring public health surveillance monitoring. He noted the need to approach this carefully to determine the best way forward.
- Ann Smith asked if there would be an opportunity to discuss how a given patient provides consent. She held her question for the portion of the presentation addressing this topic.
- Andre McGuire asked What if persons do not have access to the internet or are able to use a computer? How will people be able to opt-out before their information is shared? He also asked if this system is trying to get information from the Ryan White CareWare system? They mentioned that as far as they know in their work as a Ryan White Medical Case Manager, there was not any EHR in CT that was integrated with CareWare. In fact, there was yet another system created, Ryan White – Part B.
- Sean Fogarty responded that as they move out of the pilot phase with synthetic data this is something they have been discussing. There will be options including online, on paper through writing in and calling in to opt out. OHS would like to also have specific consumer engagement around substance use and mental health records by talking to groups related to this intersection. They are still working on it so people can opt-in and opt-out from this feature.
- Andre McGuire asked because he received an email from the Planning Council in Hartford that are concerned with their information being shared without their consent. He also asked: Is there a mechanism for individuals to find out about this before sharing happens.
- Sean Fogarty responded that yes, OHS is working on the messaging. The CAC is first group with whom OHS is having this conversation. And this will continue so that concerns can be heard, and alternative solutions can be created if needed.
- Tekisha Dwan Everette mentioned that the CAC is also seen as a group that can help ensure that certain communities are engaged.
- Ann Smith noted that slide 28 does not include language about substance use record in the slide text, which does not align with the title of the slide.
- Ann Smith also brought up that there be a deliberate education component to opt-out because what she has experienced in terms of electronic health records sometimes puts patients in the position of not knowing what they sign off on. For example, one of her providers switched to electronic health records. When she went into the intake, they asked her to sign on to this electronically and there was not clear information for her to look at so she could read what signing off on this really meant. She was comfortable advocating for herself but was concerned about consumers who are non-native English speakers or those who are not comfortable challenging medical providers. She wanted to know more about the consumer education so that all consumers are knowingly opting-in or opting-out.
- Sean Fogarty responded that OHS is partnering with the UCONN AIMS team on the development of educational materials including webinars and other deliverables that would reach various communities with various language abilities. He would welcome thoughts from the CAC on what they think might be effective. He also felt that there could be a few slides that could be added to address Ann's question.

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- Velandy Manohar agreed with Ann Smith's comments related to consent aligning with CLAS standards. He noted that as a provider he is concerned about non-native English speakers and what will be done to ensure that these patients are appropriately informed.
- Sean Fogarty agreed that CLAS standards are a high priority for OHS.
- Laura Morris chimed in that the consent regulation development is an iterative and robust process. OHS is looking to the CAC to support these efforts to make sure that disparate communities are being reached. As more information and feedback is gathered, these consent policies will be refined, and the internet will not be the only way to grant consent.
- Velandy Manohar suggested Khmer Health Associates, an organization serving a South Asian population, would be great to engage in these efforts.
- Terry Nowakowski mentioned the indigent, homeless, and deaf and hard-of-hearing populations and individuals with cognitive disabilities. What will people be told is the added value to having their information shared through Connie.
- Tekisha Dwan Everette responded that Connie will improve the quality and treatment of care and patients will have access to their own record. She noted that this will be discussed in more detail later in the presentation.
- Sean Fogarty added that the way they envision Connie is a network of networks, a federated model that will not be a repository that holds records. Instead, records will be stored in the cloud. Medical records will be able to be accessed in real time. It will still live where the record is developed.
- Adrienne Benjamin: What is the process for patients? Will each doctor/provider have this opt-out process? Will there be a new HIPPA/Connie form that will be sent to every provider? I guess I do not understand how this will work on a granular level.
- Sean Fogarty responded that there will be a new form at the primary care provider, but the goal would be that people can have a deeper level of preferences being respected. The caveat is that this primary provider is enrolled into the Connie system. If not, then that individual would not get that new information until their provider is enrolled.
- SB Chatterjee asked for a copy of this presentation.
- Ann Smith noted that in the beginning of the deck, there was a complicated slide depicting PHI and arrows. There was also an image of Connie in a cloud showing where the data would go if she had seen that slide first it would have been clearer. She thinks there needs to be greater clarity that Connie is not a repository, but rather a transmission system. She also felt there was not information on how robust the encryption and the security information are when data are being transmitted.
- Sean Fogarty appreciated the feedback and mentioned that that figure could be moved up. He also explained that the Core Data Analytic Solution (CDAS) is the engine of the HIE is being developed by the UCONN AIMS team. The goal is to make this high trust certified, which is the highest standard for networks and security. He can get more information on that, and additional technical and laymen slides focused on this information.
- Terry Nowakowski mentioned that homeless and transient populations may be a group of people that should be engaged. This engagement could include community providers that have shelters and organizations and providers who address food insecurity, housing instability or

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poverty. Those clients that are most vulnerable could potentially benefit from a coordinated care approach.

- Sean Fogarty responded that community and advocacy groups will be part of engagement.
- Taylor Edelmann asked: Does anyone know how this will interplay with Unite Us (a company that is helping social service/community service organizations communicate easier)? He was curious since he heard that they do a "universal consent" to share client info. Several hospitals and clinics are starting to enroll with them. There is a lot of information going around so he wanted to know more.
- Laura Morris noted that the CT Hospital Association has partnered with Unite Us and the State Employee Plan will be interfacing with Aunt Bertha. There is a need to figure out how these systems interplay with Connie
- Velandy Manohar mentioned that he is happy to see that CT Medical Society's HIE is being engaged in Connie.
- Sone Phrommavanh asked if Connie allows international collaboration.
- Sean Fogarty responded that the focus of Connie at the moment is the tri-state area, where the majority of residents may be receiving care, but agreed that there are many residents that travel and are giving their consent to opt-in and there may be a use case to explore.
- Adrienne Benjamin added: we must realize that there's tons of mistrust for things like this. We all have heard of data breaches, even for massive corporations and government agencies. There is going to have to be a powerful public appeal, with anecdotes to explain the benefit of this. She also asked if DDS would be engaged.
- Sean Fogarty acknowledged the history of data breaches that have occurred. Since Connie is a transmission system and not a repository, it is less of a target. He also noted that OHS is doing as much outreach as they can and they will reach out to DSS.
- Terry Nowakowski suggested expanding consumer engagement to school-based health clinics and FQHCs.
- Adrienne Benjamin commented that usually the consent forms are in "lawyer English," not regular person English. If possible, shorten to one page, non-professional language
- André L. McGuire stated that the Greater Hartford Ryan White Planning Council and New Haven Ryan White Planning Council and the Connecticut HIV Planning Consortium are all vital to pass information on to and receive input from those living with HIV.
- Tekisha Dwan Everette facilitated a discussion around the following question: When creating regulation on consent policy, what would be most important for individual consumers to know/understand?
- Terry Nowakowski felt that knowing and understanding that Connie is not a repository is key.
- Velandy Manohar attested to the benefit of an HIE as a connection hub as a provider. The benefit to the individual related to time and accuracy as it relates to delivery of care is important.
- Andre McGuire also felt the following was most important for consumer to know: who will receive the information, for what and how long will it be used are the items that he feels would be important for consumers to know.

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- Sean Fogarty responded that they could provide concrete examples to tangibly explain to consumers how Connie would help them in the moment.
- Velandy Manohar added that the following information was important: How long is the permission valid for, how do you take it back, and how do you control who the information goes to.
- SB Chatterjee mentioned that he had provided at least two public comment to the HITAC sometime in the last year. He felt that that the basic web portal has limited availability to patients, specifically those without the technological capacities. He wanted to know: what is the progress of the availability of information beyond what is being made available via electronic platform?
- Tekisha Dwan Everette posed the following question to the group: Were any aspects of the presentation or specific topics that were confusing?
- Velandy Manohar asked how much with the HIE cost (the state) and how do we pay for it?
- Ann Smith felt that the graphics are overwhelming and some of the slides have a lot of text. If there is a way for that to be condensed so it is more easily understandable less dense text and to incorporate more simplified graphics would be helpful. Also, she had mentioned having Slide 30 being placed presentation. She noted that it is difficult for people that we want to reach to grasp some of this information at the level it is currently being presented.
- Terry Nowakowski noted that if there was evidence from other states on how an HIE has improved outcomes or other positive benefits, that could be helpful to include.
- Tekisha Dwan Everette asked the group: Is there any additional information about HIE consent that you want to know?
- Ann Smith reiterated that it would be helpful to include a real-world example or demonstration of flow chart of how Connie would work out and what would it look like if you were in your providers office. The current graphics depict the big picture and provide a high-level outlook of the HIE. She suggested drilling down to examples of how will Connie look for people in their doctor’s office, what will I be asked to sign, how will it work electronically? Having these patient-specific scenarios will help consumers with understanding what to expect.

Committee Reports

Velandy Manohar

- Velandy Manohar reported on the Consumer Engagement and Outreach Committee meeting on September 10th, 2020. The committee members suggested that they submit feedback to Mathematica as soon as possible in advance of the report submission.
- Terry Gerratana provided procedural guidance that the letter would be presented to the CAC which the CAC would be able to discuss. The final draft would be approved by the CAC chair.
- Bob Krzys provided the context of the letter. The standing sub-committee is targeting events related to long-term care facilities and impact on COVID-19 and LGBTQ. Mathematica was awarded a contract to do an independent review of what went wrong in the state of CT and proposing recommendations going forward. The sub-committee met with Mathematica earlier in August, of which many of the comments seemed to be included the report. The interim report, which was published, however the CAC want to present their feedback to Mathematica to incorporate in the final report. It asks Mathematica to embed a racial equity lens and to include an expanded analysis on types of facilities and the associated outcomes. He mentioned

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	<p>a recently published study about unionized nursing homes in New York State. He mentioned that Velandy Manohar had submitted a request for additional feedback. Bob Krzys summarized the addition to the draft comment letter.</p> <ul style="list-style-type: none"> • Velandy Manohar explained his reasons for requesting the inclusion of his additional feedback, as these were key to maintaining healthy outcomes for staff and residents. • SB Chatterjee agreed with Velandy Manohar’s additional suggestion and the differences in quality between for-profit versus and non-profit. He mentioned that taking shortcuts at the margins can be detrimental. He also referred to a biannual quality review system is warranted for long-term care facilities. • Adrienne Benjamin mentioned that recently DPH will not be giving out PPE equipment to homecare providers. These homecare providers go to homes of vulnerable sick people who are not at the level of nursing home but near it. Community First Choice is not 24-hour care. While not direct to nursing homes, she wondered if they should note their alarm for this measure as this is tangential for those who opt for care at home. She did note that for some families it was not reasonable for their family members to remain at home for the sake of the caregiver. What is needed is for nursing homes to provide quality care. She wanted to make sure that there is an understanding that both home-health care and nursing homes are needed and that these issues are tangential. She asked if there is a process to make a statement conveying the concern and alarm about this occurrence. • Velandy Manohar agreed that highlighting that people staying in the home is ideal but agreed that nursing homes are also important. • Terry Gerratana mentioned that this letter is specific to the Mathematic report. She did add that CAC members that are concerned about this specific DPH regulation can send their comment directly to DPH via email. • Bob Krzys moved to adopt and approve sending the feedback letter to Mathematica with additional feedback: Request that Mathematica consider including a recommendation that Long-Term Care facilities have a designated Infection Control Officer to ensure that all applicable preventive safeguards are in place; that they are communicated to staff and residents; and that there is a process for tracking compliance with the safeguards and a plan to correct gaps in compliance. Alan Coker seconded. The motion carries. • Taylor Edelman reported on the LGBTQ event in January or February, a moderator with 4 – 5 panelist including providers, patients to have a discussion for health equity and what that looks like. He wants for this event to be open to and welcoming of all ages. The length will be 1.5 – 2 hours. There will be a meeting in early October to help draft a panelist recruitment email. • Terry Gerratana reminded that the next full council meeting would include a meeting about the CHWAB. 	
6.	Adjournment	Terry Nowakowski
	The meeting adjourned at 5:29 PM.	