Consumer Advisory Council
Meeting Minutes
March 9th, 2021

Meeting Date	Meeting Time	Location
March 9th, 2021	3:00 – 5:00 p.m.	Zoom Meeting

Participant Name and Attendance

Jeffrey G. Beadle		Christiane Pimentel	X	Adrienne Benjamin	X
Alan Coker	X	SB Chatterjee	X	Peggy Lampkin	X
Robert Krzys	X	Soneprasith Phrommavanh	X	Andre L. McGuire	X
Velandy Manohar		Taylor Edelmann	X	Daniel C. Ogbonna	X
Terry Nowakowski	X	Ann R. Smith	X		
Others Present					
Terry Gerratana (OHS)		Dashni Sathasivam (HES)		Tina Kumar (OHS)	
Ormand Clarke (OHS)		Vatsala Pathy (Cedarbridge)		Leslie Greer (OHS)	
Michele Scott (Consumer)		Carole Robinson (Cedar Bridge)		Krista Moore (OHS)	
Lorrie DeLeon (Consumer)		Jamal Furqan (CedarBridge)			

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, January 12th via zoom. The meeting convened at 3:03 p.m. Terry Nowakowski chaired the meeting.	
2.	**Public Comment**	Terry Nowakowski
	Michele Scott provided a public comment regarding the Disparities Profile discussed at the last meeting. After reviewing it, she had some major concerns regarding the inclusion of the Mashantucket-Pequot Tribal Nation but not any other tribal nations in the counties identified given that the title specified Middlesex County, New London County and the Mashantucket-Pequot Tribal Nation. New London county has three tribes within it, so to identify just Mashantucket-Pequot is problematic. Do the demographic numbers included under the Native American racial categorization specific to only the Mashantucket-Pequot or does it cover everyone in the Uncas Health District, is it anyone who identifies as Native American. One of the examples was SNAP benefits. Are we are saying the Mohegan and Eastern Pequot Tribal Nations are not counted in the 158? She also brought attention to the fact that the Mashantucket-Pequot reservation is adjacent to Preston and Ledyard. Taxpaying Native American Ledyard residents that are Mashantucket Pequot members have been denied social services. If you are not intimately familiar with these dynamics. If we have a profile that singles out the Mashantucket-Pequot Tribe, but then the demographic reflects a general Native American category, then who are we talking about and what is the purpose? She people to be aware that there are many tribal nations and many people living in Connecticut from other tribal nations outside of Connecticut.	

	SB Chatterjee shared that the Office of Minority Health received new funding related to COVID-19 as a possible helpful resource: https://www.minorityhealth.hhs.gov/toolkits/FOA2021_Toolkit.aspx?utm_medium=email&utm_source=govdelivery Peggy Lampkin asked for clarification regarding the listed adult health outcomes, what are the outcomes. We have identified the inequities, and it is fine to identify them, but she would like to understand what has the county done or doing about this after these inequities have been identified. This is not clear to her. Terry Gerratana said she would review the report and follow up with Peggy Lampkin.	
3.	Approval of the February 9th Meeting Summary	Terry Nowakowski
	The motion was made by Terry Nowakowski and seconded Alan Coker by to table the approval of the minutes of the Consumer Advisory Council meeting of February 9th, 2021 minutes. Motion carried.	
4.	CT Statewide HealthIT Plan Consumer Engagement Presentation	Vatsala Pathy & Jamal Furqan, CedarBridge
	• Terry Gerratana introduced the CedarBridge group facilitators. • Vatsala Pathy provided an overview of Connecticut's 5-year State HIT plan development process sharing that they are in the early stages of gathering consumer input and feedback through a series of the topically-focused virtual feedback session. This session featured text and online polling. • Connecticut General Statute 17b-59a(3)(c) is the statute requiring the creation of the State HealthIT Plan. This plan is intended to be finalized by the end of 2021. The process of developing the plan includes hosting virtual stakeholder forums, conducting electronic surveys and key informant interviews. Draft recommendations will be presented to the HITAC. That draft will be taken back to consumers for another round of stakeholder feedback before being drafted into a draft plan and the finalized for HITAC and OHS's approval. Ultimately this document will be presented to the legislature. • The goal of the presentation was to gain the CAC members current perspectives on the healthIT and data Landscape in Connecticut. • Discussion question: How do you currently access your own health records? • MyChart and online records were commonly cited. Otherwise, members said they would have to go to their provider or provider's office or the medical records department of a health system. Peggy Lampkin responded that unless she accessed her records online, she would have to go to medical records office. • Poll question: are you currently able to access your medical health information when you need to? • The majority of people responded having some or most clinical health records available. Only one responded that all of their health records were available to them. • SB Chatterjee asked if they have an assessment on the providers in Connecticut in terms of how far the automation of electronic records have matured given the funding and incentives that have been offered? Is there a survey? • Vatsala Pathy responded that she was not sure, but thought that OHS was conducting a survey of how the funding was allocated and what was success in getting providers on electronic record? • Poll question: How do you currently access your medical health records?	

- The majority of the CAC responded that they log onto a single provider's website (patient portal).
- Vatsala Pathy asked if people were on systems other than EPIC? And for those receiving records in a digital record, is that on a CD or flash drive?
- Alan Coker responded that he receives mailed paper copies.
- Question: How many different patient portals do you have access to?
- Responses varied between having just one portal with their primary care provider versus several portals across multiple providers.
- Adrienne Benjamin asked if CedarBridge is doing these sessions throughout the state or if the CAC is the only consumer group? The people on the CAC are not representative of the average Connecticut consumer and they have more time, and access to the internet access and information. She is worried that their opinions and responses as more representative than they actually are.
- Vatsala Pathy stated that They will be having multiple stakeholder sessions, though the questions to the CAC were tailored specifically for this group. She understood Adrienne Benjamin's concerns and CedarBridge would continue to explore how to make their efforts more robust stakeholder input. Given their previous extensive work in Connecticut and with OHS for 4.5 years, they are familiar with the Connecticut landscape and helps position them to ask the right questions and filter through the feedback to make sure they are not disproportionately taking a certain viewpoint. Also, this is qualitative data collection.
- Adrienne Benjamin added that the question asking if their providers were using EPIC was not something that the majority of the average consumer would understand
- Ormand Clarke asked by what means do they intend to engage the average citizen?
- Vatsala Pathy shared that those are ongoing conversations with OHS and she does not have a definitive answer at the moment, but they have a strong commitment to making that happen. They are open to suggestions, thoughts and ideas They are also going to be disseminating a number of electronic surveys.
- Terry Nowakowski mentioned that there are many hospitals in Connecticut that are in different systems and that depending on which hospital you end up indicates which system you are in, but she has a solo provider that isn't in any system. So, she would be representative of this kind of consumer.
- Ann Smith stated that when she hears that there has been 4.5 years of experience that CedarBridge has had, there is value in that, but there is also the specific knowledge has been gained in the past year during the pandemic. She is also concerned that a plan for garnering consumer engagement has not been finalized and in place yet. There is a tendency for policies to be developed prematurely based on concepts and biases from what we have done before without giving credence and importance to other input, which end up being solicited but not incorporated into the structure and design of the information gathering process. It concerned her to hear that.
- Vatsala Pathy responded that from their perspective they are committed to ensuring that the engagement with consumers isn't just something that fulfills a checkbox, but is meaningful. She understands that that is a real concern. They will take this back to OHS to find ways to action this.

- Discussion question: Do you feel like your providers typically have enough information on your health history to provide quality care?
- The majority of responses had a common thread that there has not been enough information that is being shared between providers.
- Sone Phrommavanh felt that his PCP had enough information for his care, but he is concerned about patients that do not speak English with proficiency. He provided the example of his mother and that every doctor she visited did not have enough information and she was unable to advocate for herself.
- Vatsala Pathy agreed and resonated with Sone's statement and asked how things could be improved.
- Sone Phrommavanh responded that there is a great deal of variance in the delivery of care. For example, one provider might say you cannot translate for your parent, but another physician may be fine with it, but say that your parent must consent. But if you don't speak the language how do you consent. There is no standard practice across the board.
- SB Chatterjee agreed that he can see the difficulty related to differences in language and culture. He referred to a CLAS Standards report by Connecticut Multicultural Health Partnership and Department of Health the CLAS Presentation deck can be found here: https://portal.ct.gov/-/media/DPH/Office-of-Health-Equity/Main-Page/Publications-and-Presentations/CHE2015v7postingpdf.pdf?la=en
- Ann Smith clarified that CLAS standards work is ongoing and that they would be a good resource to contact around what they have observed in implementation of CLAS standards. She also referred to Sone Phrommavahn's story about accompanying a parent to care, adding that there are providers who discount (unintentionally or not) the credibility of their patient's complaints so their reports are not taken seriously. She mentioned that cultural competence is critical to quality health care delivery. If providers are not open or willing to learn about the culture of their patients then the quality of care will be lower.
- Peggy Lampkin asked if there is a role for health advocates in CT and people who could step in for an individual who, for example, doesn't speak English?
- Terry Gerratana responded that Connecticut has many community health workers that play that role as they are from the communities that they serve. Apart from this, there are some health advocates within hospital systems, she doesn't know if doctor's offices or other providers employ them.
- Discussion question: Do you have concerns on how your health information is shared between health care organizations?
- Peggy Lampkin noted that the issue has seen is that the breakdown in the system security and the history of data breaches. This has made her uncomfortable.
- Alan Coker added that his records are available to his medical providers and case managers and he doesn't know if they have good checks and balances. The agency is so big and his information feels so free to look at and that is another way to get information out to people who do not have a stake in his direct treatment or medication decisions. He doesn't think that a therapist or someone else shouldn't have his records.
- Terry Gerratana shared that one of my providers wants her to post on Facebook how my provider performed. She has been in a provider's office and they cannot access her medical

records from other providers, every time she sees a provider she brings a typed list of my medical facts.

- Terry Nowakowski is concerned about the accuracy of the information itself. As a therapist, she has read charts that have opinion in them (like noncompliance) rather than facts. Also, there her medication list is often not current.
- SB Chatterjee also asked about the duration of the data. What is the time dimension of the health records in terms of spanning one year or many years?
- Taylor Edelmann shared that pertaining to LGBTQ folks, transgender or gender non-conforming folks in particular, the way most providers speak about the patients is concerning. Using the wrong pronouns, referring to their identity as if it's a medical problem, etc.
- Polling question: Are you satisfied with the control you have over who uses, views or shares your health data?
- The responses ranged from not satisfied to somewhat to mostly satisfied.
- Polling question: How do you currently grant or restrict access to your health data?
- Responses varied between not given the ability to grant or restrict access, I complete and sign a form electronically and I have to complete and sign a form.
- Terry Nowakowski asked for clarification if this consent was at the point of care?
- Vatsala Pathy agreed at the point of care.
- Christian Pimentel shared that she has the ability to sign an ROI though she hasn't gone through with it.
- The CAC engaged in Rank Voting of the top three priorities for the HealthIT plan to address.
    1. My providers having access to my health records at the point of care
    2. Better coordination of my care across different healthcare providers
    3. Bette access to benefit information, such as copay and deductibles
    4. My ability to access my health records across different providers
    5. Ability to electronically restrict and grant access to my individual health records at any time, by record type
    6. A better approach to protecting patient privacy and health data
    7. Access to digital health tools such as telehealth services, remote patient monitoring devices, health apps
    8. Broadband internet connectivity and affordability
    9. Technology support with the use of healthIT
- Adrienne Benjamin noted that in most cases patients are not given the consent information that they are signing, otherwise it is too long and complicated and confusing for the average person to understand
- Ann Smith agreed with that. She shared about a time when she was asked to sign something without receiving the document. She noted she had to punt this issue up the chain and as an attorney she would be able to understand this, but the fact that this information is inaccessible to the majority of people means that this is not informed consent.
- Christiane Pimentel agreed with Ann Smith's statements. When she has asked in the past, individuals are not able to actually answer the question of what and why she needs to sign. There is a lack of training around this communication.
- Discussion question: Describe the ideal future state for advancing your healthcare through HealthIT and Data

	• SB Chatterjee asked about access to other services for example, COVID-19 vaccinations not reaching communities of color. He referenced how universal broadband access was just announced and this is something that is important to pay attention to. • Andre McGuire added that beyond data sharing, the major issue I see is the lack of real communication before after and during. A visit is now confined to 15 minutes and if you do not have questions when you get there you will not have answers. Also, many people need to make a choice to get to the doctor or eat and working full time. Forget about the dentist. • Adrienne Benjamin brought up the lack of affordability and health care and how many people avoid going to the doctors. How many people cannot access basic care they need because of their deductible. This may be outside of the lane • Vatsala Pathy agreed affordability is an important component and one that is outside of the scope of this, but does have impact. • Vatsala Pathy thanked the CAC for their time and participation. She asked that members feel free to email further thoughts or questions at cthealthitplan@cedarbridgegroup.com • Ormand Clarke stated that he needed to learn more about CedarBridge's consumer engagement efforts because his responses do not reflect the average consumer. He hopes to hear something more. • SB Chatterjee agreed and felt there needs to be a large sample size. For example, a town hall type of engagement, because statistically speaking the sample size is too small. • Christiane Pimentel also added that this group is not necessarily capture the majority of individuals that they are look to hear from.	
5.	Committee Reports - Consumer Engagement and Outreach Standing Committee	Robert Krzys, Terry Gerratana, Dashni Sathasivam
	• Robert Krzys announced that there will be a Membership meeting on March 24th. There will be a review of the by-laws as these were founded on a concept of attendance and term limits, which were put in place to continually bring in new voices and the group. Attendance of all members will be reviewed at this meeting. The group will also need to figure out how to apply these term limits (two 3-year terms) to those who have been on the Council for many years. Robert Krzys stated that he does intend to resign in June to honor the term limits. He recognized that maybe there will be exemptions because these policies were new and there was a pandemic etc. • Terry Nowakowski noted that the Community Outreach and Engagement did not meet this month. • Dashni Sathasivam shared the Facebook live statistics: 2563 people were reached. 285 reactions, comments and shared. This recording is currently living on the Commission's Facebook page, but OHS will still need the recording file. • Terry Gerratana clarified that people will be able to see the entire program on Facebook. • Alan Coker provided congratulations to Taylor Edelmann and Dashni Sathasivam for their outstanding work. • Terry Nowakowski shared that she felt the CAC has struggled to get people in the past and that this is a new path. • Terry Gerratanna agreed that it has been wildly successful and something for OHS to think about for future engagements to reach more people.	

	• Terry Nowakowski agreed especially given the new standards for WIFI and in hopes of reaching communities that have historically been harder to reach. •	
5.	OHS Listening Sessions	Terry Gerratana and Dashni Sathasivam
	• Dashni Sathasivam provided an update on the OHS listening sessions and the groups that have been engaged. She shared that two sessions have been conducted with CHWs in partnership with the CHW Association Connecticut. She thanked Pastor McGuire for his help in connecting with the community of individuals living with HIV/AIDS. • Terry Gerratana added that OHS and HES is hoping to get more participation from more groups. She also briefly summarized the previous meeting featuring Jenn Searles, Connie's Executive Director.	
7.	New Business/Announcements	Terry Nowakowski
	• Alan Coker shared that he will no longer be serving as the co-chair after the next Membership Committee of the Council. • Lorrie DeLeon introduced herself. She lives in Suffield Connecticut 2 boys with juvenile onset bipolar disorder. Her focus is bringing attention to families with children dealing with this major health care concern. • Terry Gerratana reminded everyone that the next general CAC meeting will be held on April 13th and she is working on the agenda which will feature one of the ongoing initiatives of OHS. • SB Chatterjee voiced that he feels that medical reconciliation is important. • Robert Krzys clarified if Michele Scott's application would be taken up by the Membership Committee. Also, he urged Lorrie DeLeon to consider becoming a member of the CAC as she is exactly the types of voices that are needed. • Terry Gerratana shared that there will be a notice for soliciting members which would be posted by the end of the week. • Terry Nowakowski also asked CAC members to consider individuals in their networks and share the application with individuals and urge them to apply. • Bob Krzys reminded people to review the bylaws as there are specific types of people that the CAC is looking to engage. • Dashni Sathasivam also shared that the Commission on Women, Children Seniors, Equity & Opportunity have just released the LGBTQ Network survey. https://bit.ly/3siusqC	
8.	Adjournment	
	Terry Nowakowski moved to adjourn the meeting. Alan Coker seconded. Motion carried. The meeting adjourned at 4:59 PM.	