HIV Community Advisory Group Meeting Minutes
September 24, 2019; 10:00 a.m. – 2 p.m.
Gifford Medical Center, Randolph VT

Attendance: Mike Bensel, Pride Center of VT; Laura Byrne, H2RC; Daniel Chase; Pat Gocklin, DHMC; Grace Keller, Howard Center Safe Recovery; Chuck Kletecka, VTPWAC; Geoff Moore, VT PWA Chair; Zpora Perry, UVMMC; Karen Peterson, APSV; Paul Redden III; Taylor Small, Pride Center of VT.

Remote Attendance: Peter Jacobsen, VT CARES
Vermont Department of Health: Daniel Daltry, Erin LaRose
Caracal Consulting: Alexander B. Potter
Guest: Brenda Godfrey, RN, UVM

The meeting was called to order at 10:11 a.m.

I. DISCUSSION: DVHA & CLOUD-BASED EHRs

A. Key presenters from *Department of Vermont Health Access* were planned for this meeting, but were unable to attend due to illness. Two representatives of the consultants working with the state of Vermont were scheduled to present on the 2020 migration of Vermont's Electronic Health Records (EHRs) onto cloud-based storage, and garner feedback about how best to inform and educate vulnerable populations about their rights concerning these changes. The footnotes below give a brief definition of the terms used in this discussion, including "**the cloud**," "**cloud computing**," and examples of common cloud-based applications.[1]

B. Vermont's Health Statutes have been updated, reflecting all actions of the 2018 Legislative session, including the following update to *Title 18: Health; Chapter 219: Health Information Technology and Telemedicine, Subchapter 1: Health Information Technology*. [www.legislature.vermont.gov/statutes/fullchapter/18/219] An individual's health information is currently compiled into an Electronic Health Record, stored by health providers, networks, and organizations (hospitals, clinics, pharmacies). The statute update moves storage of EHRs into the cloud, making them accessible to all providers with approved internet access.

1. The update takes effect in January 2020 with other potential deadlines for actual live implementation of the cloud-based EHR system.

[1] **Cloud** = The term "the cloud" in this context refers to ***remote storage for information***, information that has in the past been stored on personal computer hard drives or institution-specific back-ups. Documents, photographs, programs and software can be stored on, and run directly off of, the Internet rather than a local or personal computer. This offers huge amounts of storage space and increased accessibility of data; data stored in the memory of one computer is only accessible when that computer is turned on, whereas data stored in the cloud can be accessed from anywhere, by anyone who has a device with an internet connection, and has the right passwords/knows the right access procedures. Devices include smart phones, computers, tablets, etc.

Cloud Computing = The act of using "the cloud" to store and use data and software applications from any given device with an internet connection, anywhere in the world.

Common Cloud Applications = *Google Photo*, where you can store your photos on Google's servers and not use your own computer's or phone's memory. *Dropbox*, where you can create folders in the cloud to hold documents, and give access to other people so they may read and change the documents from their computers. *NetFlix*, in which you can watch could-stored films on your device, without owning or needing to rent a hard copy of the film.

2. It is possible for individuals to "opt out" of having their EHRs stored in the cloud. This will be automatically implemented, so individuals must opt out to exclude their information from storage in the cloud.
3. DVHA representatives are reaching out across the state to explain the process and results, identify where the state is at in the process, and **determine best ways to find and educate vulnerable populations** who may not receive this information otherwise. DVHA planned to present to CAG and receive feedback on how people living with HIV may respond to the change, and how best to reach populations that our providers serve with information and assistance.
4. To clarify, this **is not** a process to solicit feedback on the *overall concept of cloud storage/accessibility of EHRs* for the state of Vermont. That matter has already been determined by the statute update made by the legislature in favor of moving Vermont's health system forward technologically and meeting current standards in the healthcare field. This process is to **garner feedback** on educating people about their rights and options.

C. There was sufficient interest from CAG members that Daniel will schedule DVHA to come to the next meeting (ordinarily November, but scheduled for Tuesday, December 3rd to avoid conflict with the Thanksgiving holiday).

D. The consultants presented at the PWA Retreat. Daniel asked if Chuck or Geoff had feedback on their presentation there. Geoff said he was unable to attend most of it. Chuck said both their presentation of themselves, and their literal presentation of information, were unfortunately quite formal in tone and appearance, with the effect of appearing more authoritarian than perhaps intended. While he recognized that for the representatives this was likely seen as a more professional approach, It did not feel as though they matched their presentation style to the audience in attendance. Consumers were all very concerned about the cloud storage concept. Generally, Daniel and Chuck both heard that it was a good exchange but were uncertain that it helped attendees to be more comfortable with the concept.

1. Zpora asked if there were concerns about hacking. Chuck said this was a big concern generating a lot of questions, along with concerns about people who have ***legitimate access*** to the records, but ***no reason*** to be viewing them. Zpora reported that just from her experience with the UVM Medical Center, there are measures in place to prohibit and restrict the latter: record searches are monitored; there are strict ethical protocols for accessing records and people accessing records leave a clear "electronic footprint"; individual access is monitored and brought to supervisor attention if it is deemed questionable or inappropriate.
2. Chuck raised the concern about smaller practitioners outside a system such as UVMMC, who now have access to a much greater breadth of a given patient's medical record, but do not have the same circumscribed monitoring. Mike noted that this was a concern for the population

Pride Center serves – individuals may not want all their providers for all purposes to know they are transgender or HIV positive. Zpora said that UVMMC has the EPIC platform which is something smaller practices as a rule cannot afford. She added that her own access to the Medicaid portal is on the level of confirming if an individual is on Medicaid, if it is active, and the dates of activity – nothing further.

3. Daniel agreed that these were good issues on which to get clarification from DVHA. Karen looked up their website in the moment to check on accessibility of general answers to commonly asked questions. She was unable to find easy, clear access to the information.

E. Mike inquired how it was that this came about without people being aware of it, and why there was not more input/information gathering at the front end of the process as there has been with past changes of this nature. Daniel said he did not hear about this until Chris Fletcher contacted him with information that there was a mandate to involve stakeholders in an *educational* campaign, which was definitely a post-decision process. Often town meetings are used to discuss these changes but there was no knowledge of these happening in this case.

F. Grace noted that while she also has concerns, regarding people with substance abuse issues not wanting to seek treatment if information is more broadly linked across providers and the state provider system, she was also pleased that they chose to reach out to CAG and wanted to utilize this group to access concerns for vulnerable populations.

G. Daniel confirmed he would make sure to get the DVHA folks on the next meeting agenda. Paul asked if it required a special meeting in the interest of time. Daniel said that unless other items came up that would pressure the timeline of the next CAG meeting, there was no reason to add a meeting. He expected the agenda to be straightforward to revise – December's meeting agenda is currently planned around revisiting testing and looking at the new CDC Vulnerability Study. Lucia will be coming in from VDH to walk CAG through the new study. Daniel will assess time concerns and the meeting needs.

H. Lastly, both Zpora and Chuck noted that both of them, even in raising questions, are aware that this is in fact an effort to provide better health care. Chuck said he encouraged people to think about the fact that if you have a chronic illness, might you want your providers to all have good access to your records? It is good to keep this in mind as questions are posed and concerns raised.

I. Zpora is attending a conference put on by DVHA on October 24. If she gets additional information that may be helpful for people to see in advance of the December 3rd meeting, she will send it out.

II. VDH UPDATE

A. HRSA SUPPLEMENTAL FUNDS AWARD: The grant for HRSA Supplemental Funds, discussed at the last few meetings, has been awarded. Vermont was awarded 40% of what we requested in our application. Daniel noted that in speaking further with HRSA, VDH learned that our grant received a score of 96 and was one of the highest scores they gave, and the limited funding reflected the high demand.

1. Vermont's grant sought funding for a housing specialist position, increased housing vouchers, coverage of Medicare Part B insurance, and establishment/expansion of medical care in a mobile setting.
2. Historically the supplemental funding has been more accessible. That we were awarded only 40%, while scoring so high, indicates the availability of these funds has been severely impacted. When speaking with HRSA and learning about the score, the HRSA representatives stated that they found the grant very comprehensive and compelling, and wished they had been able to fund more of the initiatives – they felt the approaches were new and innovative.
3. This indicates that a large number of programs are hitting harder times and there are many more applicants vying for the HRSA supplemental funds. While in the past Vermont might have been able to access $800k for a one time supplement, that is no longer the case.
4. With the incomplete funding, the plan is to (1) move forward with the creation of a hopefully full-time state housing specialist position, an individual who will work with ASOs and PLWDH to coordinate the needs of housing around the state; (2) allocate just under $100k for additional housing vouchers; (3) part b premiums. Housing has been identified as a priority both broadly in the VDH and in the Agency of Human Services overall, so there is good support for the position. Due to the 75/25 split requirement on the funding received, only a certain amount is allowed to be targeted to vouchers. We have 28 vouchers now and the hope is to move to 38 or 40, however this will all depend upon the breakout of allowable expenses from HRSA balanced against HSH budget concerns with external awards against a diminished rebate pool of funds.
5. VDH will be working with the CCC around this award to determine how best VDH can continue to support the innovative home care/medical team for individuals for whom services are hard to reach.

B. RAPID ACCESS EXPANSION: VDH HSH was approached a month ago by the ADAP leadership concerning rapid access treatment. They talked about the excellent work happening at Safe Recovery. Following the recent tour of SR, the commissioners have expressed interest in doing more similar work in other areas of the state. They heard strongly the message from people served through SR, of "when no one else wanted to deal with me, here they would help me."

1. VDH has approached ASPV about prescribing medication to consumers who want access; APSV is on board but there is a lot to learn and plan for, including who pays for what, days of availability, etc. Windham County is highlighted right now as there is a large crisis of overdoses happening there. There is hope this will increase case management for PWID in Windham County.
2. Right now, a good amount of funding exists for the next 3 years. What happens at end of that 3 years? These funds cannot be stretched out into further years. A goal is to demonstrate the need during this next 3 years with the hope that these funding streams don't dry up.

C. DISCERN PHASE II. The DISCERN study has been looking at patterns of drug use along the I-91 corridor. In their Phase Two they want to study mobile care in relation to access to treatment and dosing. They will be using mobile vans and see what they can do in terms of dosing for HCV, with a goal of making HCV treatment services more accessible.

1. Laura stated that while she was not at the meeting, her understanding is that they are proposing a research study in which one group will be offered case management linking to treatment, versus a second group linked to telemedicine

with a hepatitis specialist on line during the syringe exchange open hours. They plan to use a mobile van to connect the clients to telemedicine. They will compare to see which group has a higher success rate.

2. Karen said she was not at the meeting either, but did receive the minutes and is aware that it is now only VT and NH involved in this phase, whereas MA was also involved previously. They are trying to reach 220, through St. Johnsbury, Brattleboro, Keene – the individuals must have insurance, and if they do not, DISCERN will help them to get it.
3. Laura added that it sounded like some major pieces still needed to be ironed out – they had a hard time getting a hospital/medical center to do testing because they are a research study not a provider, and it is uncertain how the van would work around syringe exchanges. Telemedicine through internet access relies entirely on good, constant internet access, which is a problem in Vermont.

D. HCV TREATMENT ACCESS: DVHA has relaxed regulations about treatment access. A general practitioner can prescribe hepatitis treatment for treatment-naïve individuals, if certain criteria is met, for instance no cirrhosis. It is uncertain if consumers know this yet. Hopefully more practitioners will utilize the online training module created by Dr. Hale; Kelly is working hard to encourage providers to take this online training: https://www.vthcv.org/

1. Grace said she believes the providers need to be educated that this hepatitis treatment is so much more streamlined than it was before. It does not require the same weekly checks that interferon and ribavirin did; it is simple and easy to do. People are desperate to get their HCV treated. To be able to be treated in your primary provider's office is a big deal.
2. Zpora stated that HCV treatment is now offered at Safe Harbor and Robin Sherman provides it at the Chittenden clinic.

E. CARE STANDARDS: Hopefully the revision sent out to offices from VDH HSH was helpful. It is still being refined and a final version will be coming out. Thanks to all for bringing case managers to the meeting and providing great feedback.

F. PROCEDURAL SUCCESS: At Vermont Pride a reactive result was received; the van was parked on a side street and accessible throughout the day. The individual was able to get into care for further testing for self and partner, and the process rolled out through CARES and the Pride Center with great success.

G. TESTING DASHBOARD – The testing section of the Dashboard was reviewed, including much improved number in the screening, referral and follow up categories.

1. Taylor said that Pride Center has had success setting up an online appoint for people at Planned Parenthood, with the client, during their test. This works better than Planned Parenthood calling the individual at a later date.
2. Daniel added that PP would like to do 30 day initiation of PrEP treatment, but there were instances where people were not getting a call for three weeks. He congratulated Pride Center on a great adaptive strategy for scheduling.
3. Taylor said in her experience, some people are most interested in incidental use of PrEP, and it is helpful that when they go to PP they hear more about the importance of constant ongoing usage. Pride Center works hard to get people information about the Gilead access plan but sometimes that doesn't come through. Homelessness is a big piece of this – understandably, housing and food takes precedence.
4. Chuck asked if there is any way we can see an indication if PrEP is working? Taylor responded that yes, indications are good: they are not seeing the

people prescribed PrEP back in testing, and they hear positive things from participants at GLAM. Daniel added that the Clinic is also seeing this.

5. Chuck asked if we had seen much regarding seroconversion after taking PrEP, and if this is something we track. Daniel stated it is now an additional question on the case report form: Have you ever been on PrEP. Unfortunately he is aware that one individual was found positive while getting a work up to get onto PrEP.
6. Daniel noted that with this review of the Dashboard we can see that we are better aligning to our epidemic! This has been a strong goal, and we are pleased to see that in anticipating around 400 tests this year, we are on track to have 50% of those be cisgender men who have sex with men. In addition he said we are seeing success at making the testing event a springboard to other interventions – leveraging the HIV test for HCV testing and risk assessment, and connecting people to other needed resources.
7. Karen commented that she loves the Dashboard and finds it a good springboard for discussion. Daniel said the data does help us serve people better and is a nice balance to the narratives we hear from around the state – it helps us see how we're doing.

II. CAG BUSINESS

A. MINUTES REVIEW: July 23, 2019

1. **Comments**: No modifications offered to the minutes.
2. Taylor moved the minutes and Laura seconded. The minutes were approved unanimously as written.

B. ANNOUNCEMENTS:

- Karen announced the APSV syringe exchange is opening in Bennington!

Meeting adjourned 12:30 p.m. with lunch.

Respectfully submitted,

Alexander B. Potter
Caracal Consulting