HIV Community Advisory Group Meeting Minutes

December 3, 2019; 10:00 a.m. – 2 p.m.
Gifford Medical Center, Randolph VT

Attendance: Kelly Arbor, VT CARES; Laura Byrne, H2RC; Peter Jacobsen, VT CARES; Chuck Kletecka, VTPWAC; Erin O'Keefe, Howard Center Safe Recovery; Zpora Perry, UVMMC; Karen Peterson, APSV; Donna Pratt, Twin States; Paul Redden III; David Schein, PWA Coalition; Taylor Small, Pride Center of VT
Remote Attendance: Pat Gocklin, DHMC
Vermont Department of Health: Daniel Daltry, Erin LaRose
Caracal Consulting: Alexander B. Potter
Guests: Maurine Gilbert and Naomi Hahr, Department of Vermont Health Access

The meeting was called to order at 10:05 a.m.

I. DISCUSSION: Health Information Exchange and Consent Policy Implementation

A. Maurine Gilbert of DVHA presented on the Health Information Exchange, regarding health records becoming digitally accessible to providers, discussed by CAG at September meeting.
1. Maurine described program, DVHA progress, and current Consent Policy Implementation.
2. Focus on design and messaging. Seeking feedback on messaging various audiences.

B. CAG members participated in exercise comparing logos and messaging (logo tag lines).
1. Strong preference for message "your doctor, your records, your choice." Why? Choice is a powerful concept and message reads clearer than others.
2. Concerns raised:
   a. Misleading aspects of phrasing. What "choice" is meant?
   b. People perceived "choice" as broader than it is meant - assumed it meant you choose which doctors get access whereas it means you can choose to opt out.
3. Other concepts?
   a. "Taking care of your medical records" felt nebulous; did not translate well.
   b. "Your records where and when you want them" immediately made people think it referred to *personal* access to records, not provider access.
   c. Pros and cons of referencing "your providers" having access – some people *want* all their providers to have easy access to all their information; others find it scary, especially if engaged in stigmatized behavior (substance use).
4. Logos: preference for green cross with radio signal, indicating wifi component. All options felt text heavy. Preference for a strong visual logo symbol expressed.
5. CAG asked: why an "opt out" option rather than "opt in"? When HIE initially market tested, **95% of respondents** wanted to participate in the linked records. Automatic inclusion with an "opt out" option therefore chosen to make it easier for the majority of Vermonters.

C. Is DHMC part of the provider information linkage? Maurine will check.

D. How is data used? Available for doctors across your care. Collected information is available *in aggregate* (no identifying information) to state for public health purposes, but any value less than 11 generates no report. Daniel noted this exceeds the HIV restriction on aggregate data, which excludes reporting for values fewer than 5.

E. Once opt in, usually takes less than a day for records to be available to providers; cannot guarantee but usually.

F. "Break glass" option: if patient needs life-saving care but is unable to consent due to lack of consciousness, providers can go into vital records system and file for emergency access. As soon as that happens, every keystroke is recorded and the provider is contacted to follow up. Exact period of time before provider has access under break glass scenario? Maurine will look into this and add to FAQ.

G. This system is similar to HIPPA regulations. HIPPA is the current means of linking medical records among providers. There is no less choice here – the linking of records already happens when individuals sign HIPPA acknowledgements and releases. If someone opts out of this system, they can still share their records through the use of signing HIPPA releases.

H. NOTE: Part 2 providers/records, which includes mental, behavioral and substance abuse health providers/records, need an extra level of release beyond HIPPA and Part 2 providers and records are not included in system. Physical therapists? Will find out and add to FAQ.

I. How do people know they have to opt out? That is what this process is for, to determine best ways to get the word out to people who most need to know that opting out is an option. March first is deadline for opt out. Change over to HIE is March 1 and once it is up and running, DVHA believe more and more providers will want to use it.

J. Do providers have to sign any agreements/acknowledge regulations? Yes, there is a business agreement on how they will use the system and how they can and cannot use the information in the system. They are also bound to "practice ethically" as in all matters.

K. HIE is particularly successful in maintaining clear medication records – standardizing allergies/sensitivities information across providers and preventing negative interactions.

L. Maurine asked the CAG to please share with DVHA ***any messaging examples that work well***.

II. DISCUSSION: COMMUNITY COALITION MEETINGS

A. David summarized for CAG the VT PWAC's recent strategic planning. Mark Price has been named new chair of board, VT PWAC is consolidating their mission, and changing their name to **Vermont Positive Living**. Lee Works raised topic that when PWAC was forming, ASOs and PWAC met regularly outside of CAG to discuss issues and meet with lobbyists. With rebate dollars going away, question has risen if these meetings should be resurrected. David wanted to bring to CAG to inquire what community members thought.

B. Daniel shared that there was a time the ASOs were coming together regularly and VDH recognizes that there may be topics providers and consumers want to engage in outside of the VDH purview, particularly items related to lobbying. Under the Hatch Act VDH cannot be involved at all with any lobbying activity. In the coming year, with the surplus of rebates decreasing, we may have to look at the language around the $475 state appropriation – if providers and consumers meet independently from state, they may be able to talk more freely about actions to take in the political sphere while keeping those dividing lines clear.

C. Questions and comments:

1. Could this meeting take place the same day as the CAG meeting?
    - Certainly. Daniel said that on the CAG meeting dates the Coalition also meets, CAG could meet until noon, then VDH and VDH contractor excuse themselves. This means no additional traveling meeting for CAG members.
2. Chuck said in past when separate meetings held, community and VDH had contentious relationship. That is not the case now. Things are working well and if we (the community) have to step back to strategize separately, it would be after trying to work within VDH. Is this additional meeting/community coalition truly needed?
    - It does provide a cleaner line between VDH and various activities the community may feel a need to discuss/take part in that fall more within political/lobbying category. Donna noted it is also helpful to share information about agencies' work that is not appropriate to take up time at a CAG meeting.
3. Positive response to piggybacking on current meetings– much better than phone meetings.
4. David agreed, encouraging the idea of making this as convenient as possible, *not* an additional meeting people need to drive to.

5. David will contact participants around the end of December/early January to talk about issues the community may want legislators to hear about, before the 2/5 awareness day at the legislature.
6. First CAG meeting of 2020 is Tuesday, February 4, the day before awareness day. The Community Coalition will meet after the CAG adjourns.

III. DISCUSSION: VDH FUNDING UPDATE

A. As reported previously, finances are getting tighter and VDH stated they would provide more information to grantees as the end of year approached and more was known. As discussed, rebates are decreasing while financial commitments are increasing, and HRSA supplemental funding came in at 40% of what was requested.

1. VDH wants to prioritize standing by the commitment to increase housing vouchers and to support the services funded under this RFA, and believe have found a solution.
2. HRSA has already given approval, and HSH Program is seeking approval from superiors within VDH, to scale back specific plans. HSH discussed that protecting base funding was priority, to secure the funding for the next three years of the four-year RFA, as awarded.
    a. Requested funding for 28 new vouchers; ***will not be able to do the full 28***. Not sure of exact number; depends on how many people get subsidies. Still under discussion.
    b. ***Will support the insurance assistance as planned***, to cover the Part B gap for consumers, as requested in Supplemental Proposal.
    c. ***Will support the mobile program*** with Dr. Devika Singh but will be ***unable to make size of commitment hoped for***. Still discussing with CCC how best to assist.
    d. ***Eliminated Statewide Housing Coordinator position***. Had good support for position but not moving forward, in specific effort to secure funding already out to grantees.
    e. ***HSH absorbing further reduction in staff*** – Roy has moved on to ADAP, and HSH will *not* be rehiring for his position, reallocating his duties among existing staff. Will drop from eight staff to seven. Feel confident this can be done successfully without interruption of service. Will be monitored by both VDH superiors and by CDC.
3. This means when next RFA comes out, it will not be at same scale. Planning body can advise on the RFA: consider questions "do you see areas that will be changing? Services that are needed more, versus no longer a priority?" CAG will do budget exercises as a group.
4. No changes or interruption in service from HSH expected – no interruption in provision of supplies, training schedule, supporting grantees.
5. Peter asked about advisability of discussing the $475 and rebate reductions at the 2020 legislative day. Would it be better to *not* push on that this year? Daniel responded that he cannot say what the best approach would be, but his belief is that none of that funding will be touched this year. Therefore, community might want to think about and determine the best timing for legislators to hear about ongoing challenges.
6. Has CAG advised on the distribution of the $475 in the past? No, CAG advised on the funding for syringe exchanges, but not on the $475,000 appropriation from the state. As that appropriation moved from state general funds to coming from the rebates, Ryan White language applied to it, and that means it must have an RFA.

IV. CAG BUSINESS

A. MINUTES REVIEW: September 24, 2019

1. **Comments**: No modifications offered to the minutes.
2. Karen moved the minutes; Laura seconded; approved unanimously as written.

B. 2020 CAG DATES: 2020 calendar of CAG dates follows; 10am – 2pm at Gifford Medical Center, unless otherwise informed.

- Tuesday February 4
- Tuesday March 24

- Tuesday June 9
- Tuesday July 28
- Tuesday October 6
- Tuesday December 8

C. ANNOUNCEMENTS:

1. David: February 5th is Legislative Day at Statehouse, starting at 9am; come as early as 8:30 to help David set up if you can! Saturday, February 15 is Drag Ball, 25th year – Silver Jubilee.
2. Peter: CARES has new Harm Reduction Manager, Martina Anderson; position open 9 months but worth the wait! Thrilled with final selection.
3. Daniel/VDH:
    a. SSP telephone meeting held November 15, reviewing new measures with grantees. Has been a journey – with infusion of funds as a part of tobacco settlement money, governor's council had clear measures they wanted to see out of that money. In community meetings in 2018 the group created measures, but at annual audit visits and in QSRs it became clear there were struggles with the measures as created. HSH worked as a team, consulted other states about evaluation of SSPs, and ultimately relaxed measures and come to a new format that hopefully will work for both grantees and the state. Last step is updating the QSR itself to reflect the changes. The team at VDH has been incredibly grateful for the year of learning with SSPs.
    b. VDH had signed on as a sponsor and endorser of a Yale research study proposal on opiates and the threat of outbreak for HIV among communities who inject. Yale was awarded this grant. Often, asked to file endorsement letters and never hear anything, but this was successful! Two year grant from HRSA Special Projects of National Significance; Yale will pay VDH to work on the spectrum of data gathering and collection, throughout the state of Vermont, under Yale's mentoring. Looking at treatment access and outbreak prevention. In addition, Abigail Cocker, a PhD from UVM, is an Evaluation Specialist working with VDH HSH. Vermont is therefore being evaluated in many different ways, which will hopefully not become taxing to consumers, and will greatly inform our services.
    c. Abigail is helping to streamline reporting requirements under an evaluation framework; hopefully we can bring front and center to this group what are we ASKING of our providers, what is it TELLING us about consumers, what do we NEED to ask, and what is the burden involved with collecting this information. An example is the questionnaire that comes with Naloxone distribution – if the client responds "yes", that they have experienced or witnessed an overdose, the form immediately launches 33 questions that must be answered each time it happens. Grantees responded to this form in particular. Theresa has leveraged NEO360 to ask those 33 questions, but all exchanges have noted that the additional questions triggered by a yes have had an effect on client reporting.
        i. Karen said at APSV clients either aren't answering the yes/no question of having/witnessing an overdose because they have realized the barrage of questions that come with the answer. They either don't answer at all, or they answer "no" even if they have witnessed/experienced an overdose. Therefore, APSV is concerned that they aren't submitting accurate data, because of the burden of data and consumer reaction.
        ii. Laura said they have had similar issues, and also noted that it is unclear how this data is being used, and the benefit it provides. In their own work, mainly Laura can report that there has been a difference in individuals accessing 911, but that is the primary information gleaned from this extensive set of questions.
        iii. Daniel agreed, and noted they have had this conversation with VDH colleagues, about data requirements spilling into direct service and noting that when data is hurting programming, that's a significant problem. A data group has formed

at VDH as a number of programs are being asked to provide feedback on many services; VDH questionnaires should operate in concert of each other and not keep adding to a data burden.

iv. Karen and Laura noted they are getting started with NEO 360 and are at a perfect time to adapt it with suggestions from Abigail and Theresa.

d. Daniel was at STD Engage conference in November and witnessed a presentation from Admiral Brett Giroir on the first-ever STI Federal Action Plan (STI Plan) for STI prevention, diagnosis, care, and treatment. He presented compelling slides on the syndemic* of the opioid crisis and infectious diseases. Kelly is currently at NASTAD conference and slide show is being presented there. In the traditional realm of HIV, STDs, Viral Hepatitis & TB, there is a growing movement to sub out TB and introduce Substance Use Disorder as part of the picture. This is encouraging as HSH works to increase its relationship with ADAP – this is a nice framework that is getting much publicity and may help build the bridges between the two worlds of ADAP and HIV.
    i. Zpora asked, in light of the information on SUD, if anyone has any thoughts on meth and how Vermont providers are seeing more of it. Zpora reported that in discussions with patients, she hears "I am addicted" language when they discuss opiates but with meth the conversation is very different. Instead she hears "it's a social thing, it's not a serious problem" and appears to be thought of as not an addiction issue at all. MSM needs around meth addiction are not being met in rehab, as those services are all opiate specific. Could we advocate with DVHA to pay for specialized treatment out of state? Not certain if there are facilities available for this, specialized to MSM meth addiction.
    ii. Taylor noted that with a client through GLAM, the only way they were able to get off meth was a treatment program in Massachusetts.
    iii. Taylor and Peter will share more information with Zpora. Taylor noted that Grace has good information as well, as people are tending to inject meth rather than smoke it, and that increases level of use and frequency.
    iv. Laura confirmed that while they only see individuals who inject meth at the needle exchange, she is seeing a lot of dual use.

e. Daniel's final announcement was that we officially have Rita Volpita back as our grant manager! She is back from leave, and she fought to keep Vermont among her regions. Sadly, LT Colonel Kathleen Davies is moving on at HRSA and will no longer be our grant manager there. Currently in the interim we will be working with Dr. Jose Ole, and are unsure if that will be for the long term.

Meeting adjourned at 1pm.

Respectfully submitted,

Alexander B. Potter
Caracal Consulting

**Syndemic: Set of interconnected health problems that have common root causes and interact synergistically, with one problem making the others worse. Because syndemics are interconnected, coordinated efforts are required across multiple programs and partners to successfully overcome the problems and consequences.*