



CONSUMERS COMMITTEE

Tuesday, July 21, 2020, 1:00 – 3:00PM

Zoom Video Call: <https://zoom.us/j/4708943670>

Committee Members Present: Lisa Best (Co-Chair), Randall Bruce (Co-Chair), Atif Abdul-Haqq, Paul Carr, Maria Diaz, Billy Fields, Asia Betancourt, Charmaine Graham, David Martin, Michael Rifkin, Leo Ruiz, John Schoepp, Rob Walker, David Klotz (Acting Governmental Chair)

DOHMH: Johanna Acosta, Cristina Rodriguez-Hart, Jose Colon-Berdecia, Lawrence Francis, Erica D'Aquila, Sarah Wiant, Guadalupe Dominguez Plummer,

Agenda Item #1: Welcome/Introductions/Review of the Meeting Packet

Lisa Best, Consumers Committee Co-Chair, opened the meeting asking to honor a grace period for late members, followed by introductions and a moment of silence led by *David Martin*.

Melanie Lawrence introduced the agenda.

Ms. Best asked us to hold on and if the minutes were sent out. *Ms. Lawrence* noted that the last minutes were for a town hall planning session and had been sent out previously. *Ms. Best* said all of the consumers needed to have the materials and a proper meeting cannot be held without all of the materials.

Agenda Item #2: Public Comment

Mr. Schoepp asked for an update on gift cards. He noted that the only two options were for Target or Amazon. He asked if a letter could be written to HASA to purchase visa cards instead. He noted the difficulty of being restricted to store cards. *Ms. Best* expressed agreement – the value of a cash card would be much more useful. The cards could be restricted to disallow alcohol and tobacco purchases. *Ms. Lawrence* noted that it is currently illegal to purchase cash cards for consumers. She also noted the current delays and barriers to purchasing just store cards. Can only use purchase orders for payment which is an additional barrier. *Mr. Klotz* tried to explain that this is federal law and would require congress to change the legislation. *Ms. Lawrence* agreed to draft a letter.

Ms. Acosta shared that emergency financial assistance is not available to everyone in NYC. The contractors are located in Tri-County but available across the EMA due to changes made by the Council to address needs from COVID-19.

Agenda Item #3: HIV Clinic Staff and Community Perspectives on Long-Acting Injectable (LAI) ART in NYC Project PROSPER (HRSA-20-078)

Presented by Sarah Wiant of COTA.

Slides will be available on our website. Following are highlights, questions and discussion.

Long Term ART is not yet FDA approved.

How much bruising is associated with the injection? Is it a large needle? How about people with a history of drug use involving needles?

Delivered in rear – many people had this concern in the clinical trial but less than 1% left due to side effects, including those associated with bruising?

What happens in another pandemic if people cannot get to the injection?

Pills would be provided to ensure continuous viral suppression.

Is there a plan to examine stigma as part of the implementation of this work?

No current plans to examine stigma. In trial, many people said it decreased their anxiety. Because its not yet FDA approved – necessary to examine this among people receiving LAI- and so waiting for FDA approval.

What is overall well being of people in the trial?

It looks to be comparable to the normal method of receiving ART

Could this be an implementation science study?

From *Cristina Rodriguez-Hart*, implementation science (IS) is a group of methods or a research methodology that studies how you get evidence based practices out into practice in the real world. There are many implementation science frameworks out there – is one being used to ground the study. IS can be used to evaluate determinants and would be useful in this instance.

From COTA, Using the study to guide how we will develop TA and provide trainings – we aren't looking at implementation here. Looking at knowledge attitudes and practices assessment. This is about perceived barriers. Interested to look at what practices could be useful.

Does the injection have to be in the glutes?

The injection was formulated specifically to be administered to the butt.

What are you asking of the Consumers Committee with regard to this work? There seem to be a lot of side effects, and its concerning that there isn't more data.

Want to discuss this technology, since its coming, and we want to be sure that we and providers are ready to inform consumers with pertinent information to ensure concerns are aired out.

The request to come to the committee was very short notice – can COTA come back and share more information at a later date.

Happy to come back and hopefully can bring a clinician to address some of the clinical questions.

Would we have to go to the doctor every month?

Currently formulated for every 4 weeks, with up to 8 weeks of protection. Hope to see a longer coverage period in the future.

What if you need a regimen change – or you have an allergy?

In some initial studies- would start patients on the oral form to ensure no issues. In real practice, will have to see how it is rolled out.

Where is this with FDA approval?

Our study has no human subjects – so we don't need FDA approval – no clear timeline on when exactly approval will come.

No timetable on when longer acting shots will be available.

How will insurance impact this?

Can do some research on this.

What about people with transportation issues?

Programs would be responsible for supporting transportation issues

Will there be genotyping to ensure person doesn't have resistance?

Need to do more research

In a pill form, how long until they transition?

Not sure if this is how it would be rolled out, but in studies its 4-8 weeks before transition to LAI.

How are the rates of suppression?

They are the same. Injection is not necessarily faster in uptake.

Agenda Item #4: Brief Policy Update on Possible Increase in Costs to Consumers

Adrian Guzman, Director of Policy in the Bureau of HIV presented on co-pay accumulators, outlining a current push from this administration that will benefit insurance companies at a cost to consumers. While typically more common in employer sponsored health plans – they are now popping up in more places. This became possible with the passing of the Affordable Health Care Act. A few months ago – Trump administration approved a rule that allows certain health plans to determine if they will impose co-pay accumulators on their clients. The more expensive the medication is – the more cost to the insurance plan. As of May 2020, there is a rule that makes it easier for health plans to adopt co-pay accumulators by excluding drug manufacture coupons and PAP payments. Many people with HIV depend on cost sharing assistance to afford their medication.

How does this affect ADAP – NASTAD says it is unlikely to impact ADAP, PrEP assistance and Ryan White funded medication. States can pass laws to prohibit accumulator policies – but its unclear which would supersede – state or federal law. Beneficiaries should call their insurance policy's number for pharmacy benefits and get the

details on whether or not your insurance company allows co-pay accumulators. VOCAL is actively working on this issue but has been stymied by COVID. *Ms. Betancourt* will keep us updated.

Agenda Item #5: Business & Planning the Upcoming Session

Ms. Best: 15 minutes would not be enough time to go through the business of the committee and that she no longer recognized the meeting. *Ms. Best* said she felt that she had not been consulted on the agenda and it should be up to the chairs and the committee to determine the agenda; the consumers have a list of very important items that cannot be run through. *Ms. Best* said the presenters and others had the bulk of this meeting. We need to be able to do committee work and we don't have a say in the work we want to do right now. We need to call a special meeting, or an executive session or poll the room. This is a consumers committee meeting and it is up to the consumers and chairs to make the decisions. *Ms. Best* said we need to have a discussion on what's going on with the CC and the business of the work we are to do. There are clear directions from the bylaws. Some of this stuff wasn't even in the planning session. *Ms. Best* recommended we call a special meeting, since 15 minutes of a breeze thru is not enough, and to open the floor to hear from the consumers we really don't get to hear from very much. We gave the presentations grace but we need to work on the CC work.

Mr. Walker recommended having another meeting to handle the remaining agenda items. *Mr. Carr* agreed and hoped to see the agenda prior to the meeting. *Ms. Lawrence* asked if the CC should no longer have the same break as the other committees and offered to send out surveys on the remaining items. *Mr. Bruce* said the consumer-at-large election is not in the by-laws. *Mr. Klotz* noted it is in the by-laws but last summer the sentiment was to wait until the fall. He also apologized that it wasn't handled over the last planning year. Multiple consumers agreed to reset the schedule to the fall.

By-laws have to be voted on by the full council. *Mr. Klotz* said it is okay to do so again. *Mr. Francis* totally agrees with Lisa – things get too structured and we get away from the work. The presentations are great and I share them with all different bodies. Maybe subcommittees are needed. *Ms. Best* recommended that because we are not going to get to the business that is our work, it's necessary to call a separate meeting. A lot of people did not get materials, a lot of people got notices the meeting was cancelled.

Ms. Lawrence noted that she is unclear on the body of work that is being referred to. *Ms. Best* said we need to take care of business and stop throwing the baby out with the bathwater so we can get caught up. We can't function like this. The chairs need to set and decide what is going on in the meeting, if not why are we here. *Mr. Carr* said we were working on long term survivors and then COVID happened. If we are cramming committee work at the end of the meeting.

Ms. Lawrence reviewed the short list of items (Vote on permanently holding Consumer-at-Large elections each fall upon appointment of new Council members; Recommend action steps for developing consumers resource page and inclusion of CAB guidance manual; Discuss focus of next planning session that could have been tackled during this time). *Ms. Lawrence* added perhaps should not have included Adrian, but still unsure on what work is not happening.

Ms. Best asked to pause the point of having a break in August. When Adrian was put in the agenda it knocked out the informed, deliberative discussion of consumer work. We didn't get asked to have Adrian on the policy. Some consumers did not get materials and we have another meeting in 3 minutes.

Mr. Klotz noted it is up to the chairs. *Mr. Bruce* agreed with setting another meeting. *Ms. Best* asked to pick another day. Agreed to Thursday the 6th of August. *Mr. Martin* asked for a doodle. *Mr. Klotz* agreed.

Agenda Item #5: New Business/Public Comment

No public comment.