



THE MONTEFIORE AIDS CENTER

Consumer output in focus: Rethinking consumer engagement for the 21st
century

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There are no conflict of interest disclosures for all presenters:

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Objective

- Demonstrate an alternative to CABs for consumer feedback
- Provide a template for a consumer model that better incorporates the diversity of consumers in Ending the Epidemic, and enhances their contributions to QI initiatives

“LOGIC WILL GET YOU
FROM A TO B.
IMAGINATION
WILL TAKE YOU
EVERYWHERE.”

-Albert Einstein



Question of the Day: Group Exercise

On a Scale From 1-5, with 5 being the ultimate level of consumer inclusion in quality initiatives and clinic leadership, how effective do you think your CAB is at:

1. Furthering the mission of your agency?
2. Contributing to the Continuous Quality Improvement practices in your clinic or program?

Please discuss your thoughts within your assigned chat room and be prepared to report back to the group



Ryan White: The Regs

- HRSA HAB RWHP Clinical Quality Management Policy Notice PCN15-02
 - 11/30/2018
 - Requires:
 - PLWH involvement that reflects the population served and ensures ... needsbeing addressed by CQM.....
 - Stakeholder involvement provides input on CQM activities ...
- Does not mention a CAB requirement**





The AIDS Center: Who We Are

The Montefiore AIDS Center

- **The Center for Positive Living/ID Clinic**
 - Largest HIV Clinic in the Bronx (and in NYS)
 - 2019: >3200 PLWH under care; ~ 300 new patients/year
 - HIV Primary Care, Psychiatry, Mental Health Therapy, Opioid Replacement Therapy, Dermatology, OB/GYN, Nutrition, Medical Case Management, Nephrology, Trans care, Clinical Trials
- **The Oval Center**
 - 2015
 - Status neutral sexual health care – prevention/treatment - >2100 patients
 - PEP Center of Excellence, NYCDOHMH funded PrEP provider for Bronx County, Trans care, STI screening and treatment, HIV testing and treatment, GYN, Mental Health Therapy, Status Neutral Care Management, and Psychiatry

Consumer Advisory Board: Where We Started



- In existence at the Center for Positive Living for 20+ years
- CAB activities included:
 - Monthly meetings
 - Quarterly tabling in clinic and/or for HIV/AIDS Awareness Days
- Between 2015-2018 Membership comprised of:
 - 7-9 active members
 - Mostly African American long term survivors
 - Mostly women
 - Heterosexual risk factor
 - All members were over the age of 50





Consumer Advisory Board: Problem Statement

- Not reflective of the community we served
 - Risk Factor: 33% MSM; 65% Heterosexual
 - Race/Ethnicity: 59% Black/African American; 30% White and Latinx; 4% White
 - Gender: 58% Male; 41% Female; 2% trans-identified
- Not reflective of the face of the current HIV epidemic
- Composed of a static group of individuals
- Comprised of patients who had been receiving care at CPL for 10+ years and thought everything in the clinic was “great”
- Because the epidemic is changing, our patients have busy and fuller lives with competing time commitments
- Showed little initiative in Quality Improvement or clinic activities

Consumer Advisory Board: What We Needed



**To get more feedback, we knew
WE needed to be different!**

- **We wanted a CAB that was:**
 - Reflective of our community
 - Reflective of the current Bronx HIV epidemic
- **We wanted:**
 - Patients with diverse experiences and backgrounds
 - Patients who were excited about QI and improving our clinic
 - Something flexible for our patient's schedules

Getting To Meaningful Consumer Involvement



2nd Quarter of 2018 we began exploring innovative ways to obtain consumer feedback

- Received technical assistance from Daniel Tietz, Director of Consumer Affairs, AIDS Institute

3rd Quarter of 2018 we informed our CAB members that we would be disbanding the existing CAB

4th Quarter of 2018 we:

Explored the use of focus groups for gathering consumer feedback

Decided to use PDSA cycle

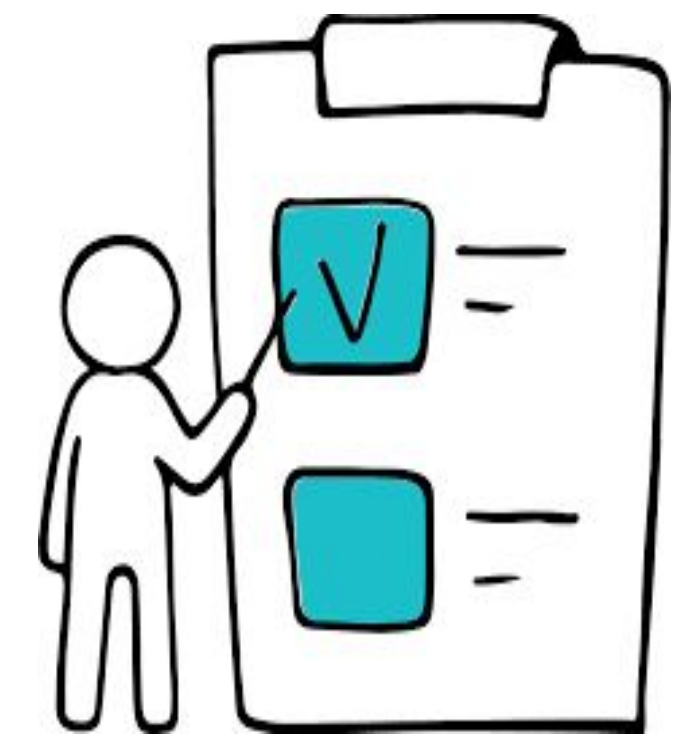
Reviewed our QI plans for 2019 and decided on the following focus topics:

Improving the new patient experience

Viral load suppression

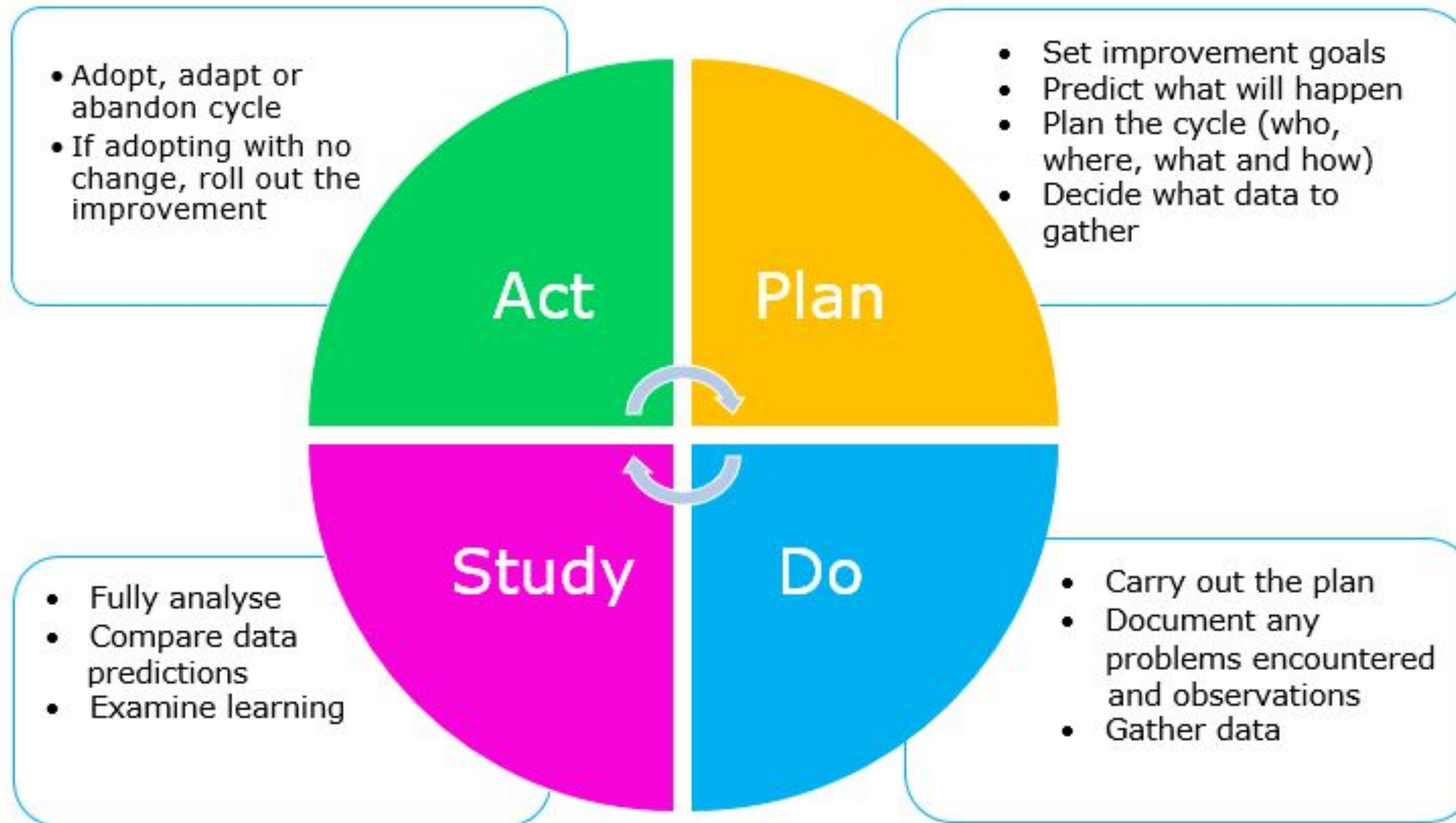
Undetectable=Untransmittable

LGBTQIA+ health services at CPL & Oval





PDSA Cycle





Why Focus Groups?

- Focus groups are a carefully planned series of discussions
- Used to gather qualitative data for QI initiatives
- Topics are specific on a defined area of interest
- Results in more diversity among participants based on the topic of the group
- Patients are part of the decision-making process
- Patients provide insight and input to improve services provided





Steps to Developing a Focus Group

- ✓ Determine goals and objectives
- ✓ Assigned facilitator(s) should include at least two staff, one facilitator and one note taker
- ✓ Determine target population and recruitment strategies (between 6-12 participants)
- ✓ Design forms for the moderator and/or note taker to use
- ✓ Determine incentives (if any)
- ✓ Develop ground rules
- ✓ Determine supplies (name tags, pens, and paper)

Analyzing Data and Writing Report



- Summarize each focus group soon after it ends
- Report should include:
 - Demographics of participants
 - Objective of the focus group
 - Focus group questions
 - Key findings
 - Recommendations
 - Next Steps (include timeline and owner)
- Meet with leadership to review and discuss findings
- Share data with clinic patients and other stake holders



Results



- **3 Focus Groups**
 - New Patient Experience
 - Virally Suppressed Patients
 - Virally Unsuppressed Patients
- **14 unique patients attended**
 - Gender
 - 7 Females
 - 7 Males
 - **Race/Ethnicity**
 - 8 Black/African America
 - 5 Hispanic
 - 1 West Indian/Asian





Our Favorite Focus Group Quotes

What suggestions do you have improve medication taking with other people living with HIV?

“Be blunt with patient. Tell them you’re gonna die!”

“Explore patient’s life events.”

What makes it easier/harder to stick to your medications?

“Knowing I gotta do what I gotta do to survive, if I want to make it; you pray on it, have faith”

“I don't want my doctor to give up on me”

"My wife used to be on top of me but when someone offered to call and remind me I was like: ‘I'm a grown man, I don't need that.’”



Our Favorite Focus Group Quotes

Which has the highest priority to your health, HIV or any other condition (*i.e.* Diabetes, hypertension, cancer, etc).

"If you have other diagnoses, try to treat them on the same level as HIV; for example people with diabetes still need to have control of both"

"Trying to stop smoking cigarettes - I got to put on my big daddy pants. HIV I don't feel like there's anything wrong with me, but cigarettes make it hard to do things I want to do... Cigarettes are killing me more than the virus, if you ask me"

What does treatment adherence mean to you?

"Doing what you're supposed to do, the opposite of what I'm doing... I think I need a day program. I stay in my room, live in an SRO full of crazy people. I'm looking at my husband's shrine and get depressed. ...staff here supports me..."

Undetectable=Untransmittable

"Why haven't more people heard about this?"

"What if you become detectable and don't know it?"



Key Findings: What Worked

- Diversification of opinions
- Focus group topics allowed us to recruit from different populations
- Valuable feedback
- Having a medical provider present to answer clinical questions
- was very helpful
- Incentives and food





Key Findings: Challenges

- Recruitment
- Planning and implementing took longer than expected
- Staff buy-in





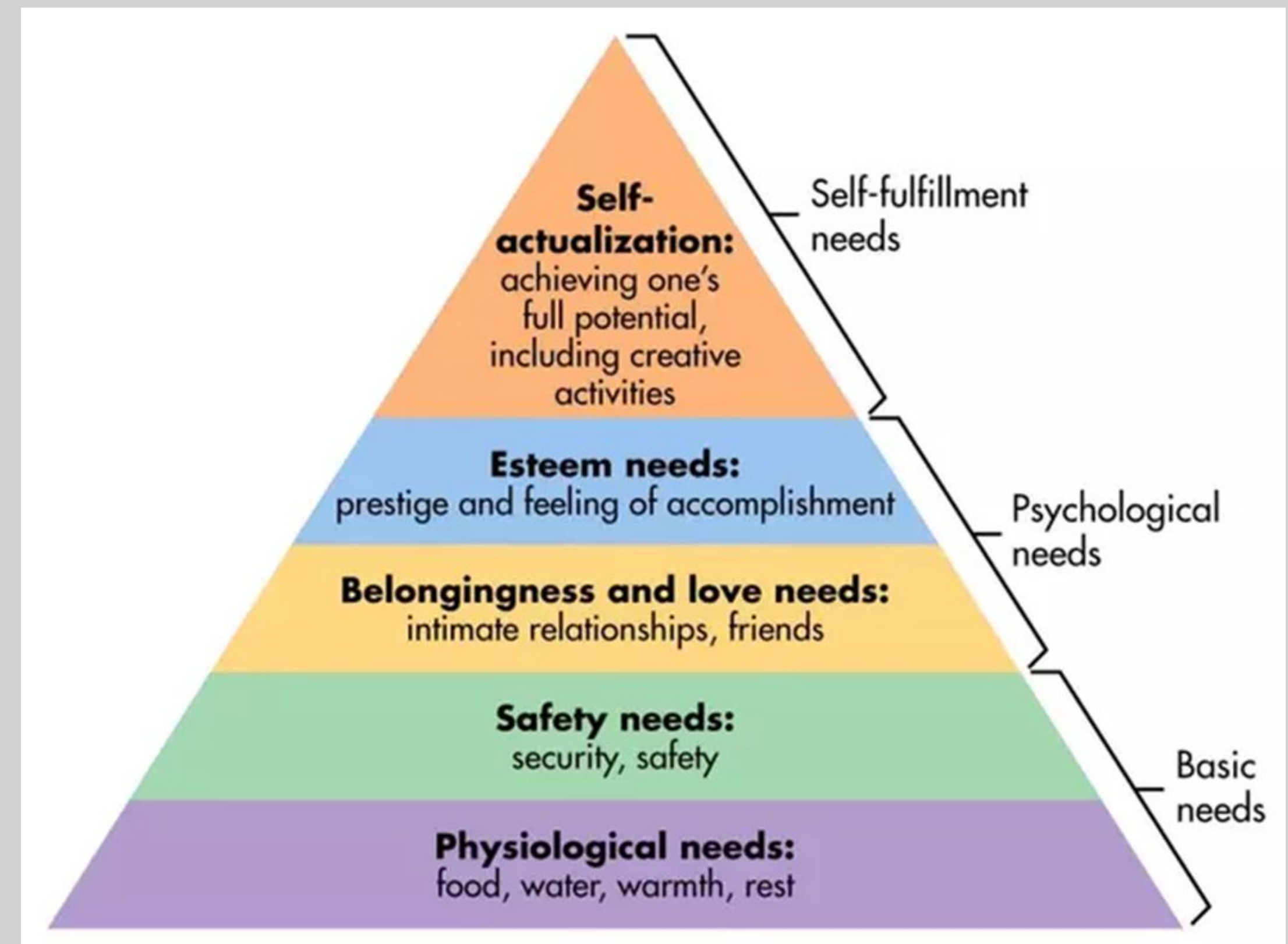
Next Steps

- Improving LGBTQIA+ services postponed till 2020
- Original 2020 Goals....
 - Increase attendance at all groups to at least 5 consumers
 - Increase recruitment at the Oval Center so that patients living both sites are included
 - Add 2 focus groups at the Oval Center specifically for patients enrolled in our prevention programs (non-PLWHA)
 - Recruitment younger patients
 - Continue to monitor outcomes using a PDSA model following each group



Consumer Involvement and COVID-19

- Real Talk
 - No one was prepared for the unique challenges and heartbreak of 2020
 - Meeting our patients where they were at
- Real Time Adaptions for the 2nd half of 2020
 - Virtual Surveys
 - Group Visit telehealth as a 'platform' for a focus group





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