# NATIONAL PARAMETER STREAMENT



# Transforming HIV Stigma and Increasing Access to Care and Prevention

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# **Objectives**

At the end of the workshop the participants will be able to:

 Describe how HIV stigma affects engagement in HIV Care and outcomes on the HIV Continuum of Care.

- Demonstrate the elements needed to implement a Trans-centric space.
- Summarize the priorities identified by the Transgender community to engage in HIV status-neutral prevention and treatment cycle.





# HIV Stigma and Progress on the HIV Care Continuum among Puerto Ricans Living with HIV

John A. Guidry, PhD (a) and Miguel Muñoz-Laboy (b)

- (a) Gay Men's Health Crisis, New York City
- (b) Temple University, Philadelphia

### **Disclosures**

The presenters have no financial interests to disclose.

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# **Learning Objectives**

At the conclusion of this activity, the participant will be able to:

- 1. Describe how HIV stigma affects engagement in HIV Care and outcomes on the HIV Continuum of Care.
- 2. Understand how participation in programs that support engagement in care may affect, or be affected by, HIV stigma.
- 3. Understand how HIV stigma varies in different sub-populations of HIV-positive Puerto Ricans.



#### **Latino SPNS Project**

- Implemented from 2013-2018
- 10 sites across the United States
  - Harlem United (New York City)
  - New York City Department of Health and Mental Hygiene
  - Gay Men's Health Crisis (New York City)
  - Philadelphia FIGHT
  - University of North Carolina
  - AIDS Foundation of Chicago
  - Core Center (Chicago)
  - Prism Health North Texas (formerly AIDS Arms, Dallas)
  - Bienestar Human Services (Los Angeles)
  - AIDS Project of Los Angeles (APLA)



#### This study on HIV Stigma in HIV+ Puerto Ricans:

- Combines datasets from GMHC's and Philadelphia FIGHT's Latino SPNS Projects
- GMHC: program participants are Puerto Rican men who have sex with men (MSM), who are HIV-positive, and have had interrupted engagement in HIV care
- Philadelphia FIGHT: program participants are Puerto Rican individuals (any gender) who use injection drugs (IDU), who are HIV-positive and have had interrupted engagement in HIV care.
- The programs concentrated on ensuring linkage to care at local health providers and providing navigation support to the clients, along with access to other services.



# Demographic characteristics of clients

Demographic characteristic	GMHC site (n=40)	FIGHT/PPP site (n=50)
Age (Mean, 95% Confidence Interval, CI)	TBD	TBD
Birthplace [ref: US mainland, % (95% CI)]	TBD	TBD
Sex/gender [(ref: Male) % (95% CI)]	TBD	TBD
Sexual orientation [(ref: Gay) % (95% CI)]	TBD	TBD
Race [(ref: Black) % (95% CI)]	TBD	TBD
Education [(ref: College or higher) % (95% CI)]	TBD	TBD
Housing status [ref: ???, % (95% CI)]	TBD	TBD
Relationship status [ref: single, % (95% CI)]	TBD	TBD
Insurance coverage% [ref: insured, (95% CI)]	TBD	TBD
Income (Mean in thousands, 95% CI)	TBD	TBD
Acculturation score (Mean, 95% CI)	TBD	TBD

<sup>\*</sup> P < 0.05; \*\* p < 0.01; \*\*\* p < 0.001



# Main findings

- The main findings of the analysis will be written here in plain language. We have not yet, however, obtained the data from the cross-site evaluation group at UCSF. They have promised the data for this week.
- Thus we will have two or three main findings to report here



#### Relationship of stigma to ART prescription at 6 months

	Model 1	Model 2	Model 3	Model 4	Model 5
HIV-stigma score at baseline	Data TBD				
Depression score at baseline	Data TBD				
Ethnic-race stigma score (baseline)	Data TBD				
Resiliency score at baseline	Data TBD				
Interaction 1: HIV stigma baseline * Depression score at baseline	Data TBD				
Interaction 2: HIV stigma * Ethnic race stigma baseline	Data TBD				
Interaction 3: HIV stigma * Resiliency baseline	Data TBD				
Age	Data TBD				
F-model	Data TBD				
R-model	Data TBD				
Significance, model	Data TBD				



#### Relationship of ART prescription at 6 months to changes in stigma

	Model 1	Model 2	Model 3	Model 4	Model 5
Changes in HIV-stigma score (baseline – 6 months)	Data TBD				
Change in Depression score (baseline – 6 months)	Data TBD				
Change in Ethnic-race stigma score (baseline – 6 months)	Data TBD				
Change in Resiliency score (baseline – 6 months)	Data TBD				
Interaction 2: Change HIV stigma * Change Depression score	Data TBD				
Interaction 4: Change HIV stigma * Change Ethnic-race stigma	Data TBD				
Interaction 6: Change HIV stigma * Change Resiliency	Data TBD				
Age	Data TBD				
F-model	Data TBD				
R-model	Data TBD				
Significance, model	Data TBD				



#### Relationship of stigma to retention in HIV care at 6 months

	Model 1	Model 2	Model 3	Model 4	Model 5
HIV-stigma score at baseline	Data TBD				
Depression score at baseline	Data TBD				
Ethnic-race stigma score (baseline)	Data TBD				
Resiliency score at baseline	Data TBD				
Interaction 1: HIV stigma baseline * Depression score at baseline	Data TBD				
Interaction 2: HIV stigma * Ethnic race stigma baseline	Data TBD				
Interaction 3: HIV stigma * Resiliency baseline	Data TBD				
Age	Data TBD				
F-model	Data TBD				
R-model	Data TBD				
Significance, model	Data TBD				



#### Relationship of retention in care at 6 months to changes in stigma

	Model 1	Model 2	Model 3	Model 4	Model 5
Changes in HIV-stigma score (baseline – 6 months)	Data TBD				
Change in Depression score (baseline – 6 months)	Data TBD				
Change in Ethnic-race stigma score (baseline – 6 months)	Data TBD				
Change in Resiliency score (baseline – 6 months)	Data TBD				
Interaction 2: Change HIV stigma * Change Depression score	Data TBD				
Interaction 4: Change HIV stigma * Change Ethnic-race stigma	Data TBD				
Interaction 6: Change HIV stigma * Change Resiliency	Data TBD				
Age	Data TBD				
F-model	Data TBD				
R-model	Data TBD				
Significance, model	Data TBD				



#### Relationship of stigma to viral suppression at 6 months

	Model 1	Model 2	Model 3	Model 4	Model 5
HIV-stigma score at baseline	Data TBD				
Depression score at baseline	Data TBD				
Ethnic-race stigma score (baseline)	Data TBD				
Resiliency score at baseline	Data TBD				
Interaction 1: HIV stigma baseline * Depression score at baseline	Data TBD				
Interaction 2: HIV stigma * Ethnic race stigma baseline	Data TBD				
Interaction 3: HIV stigma * Resiliency baseline	Data TBD				
Age	Data TBD				
F-model	Data TBD				
R-model	Data TBD				
Significance, model	Data TBD				



#### Relationship of viral suppression at 6 months to changes in stigma

	Model 1	Model 2	Model 3	Model 4	Model 5
Changes in HIV-stigma score (baseline – 6 months)	Data TBD				
Change in Depression score (baseline – 6 months)	Data TBD				
Change in Ethnic-race stigma score (baseline – 6 months)	Data TBD				
Change in Resiliency score (baseline – 6 months)	Data TBD				
Interaction 2: Change HIV stigma * Change Depression score	Data TBD				
Interaction 4: Change HIV stigma * Change Ethnic-race stigma	Data TBD				
Interaction 6: Change HIV stigma * Change Resiliency	Data TBD				
Age	Data TBD				
F-model	Data TBD				
R-model	Data TBD				
Significance, model	Data TBD				



#### Effects of medical history, interventions and background on stigma

PART 1	Model 1	Model 2	Model 3	Model 4
Medical HIV appointments past 6 months (Q76)	Data TBD	Data TBD	Data TBD	Data TBD
Years living with HIV	Data TBD	Data TBD	Data TBD	Data TBD
Medical HIV history_CD4 count	Data TBD	Data TBD	Data TBD	Data TBD
Medical HIV history_First_Care	Data TBD	Data TBD	Data TBD	Data TBD
Medical HIV history_Prescription	Data TBD	Data TBD	Data TBD	Data TBD
Level of HIV care indicator	Data TBD	Data TBD	Data TBD	Data TBD
Birthplace	Data TBD	Data TBD	Data TBD	Data TBD
Sex/gender	Data TBD	Data TBD	Data TBD	Data TBD
Sexual orientation	Data TBD	Data TBD	Data TBD	Data TBD
Race	Data TBD	Data TBD	Data TBD	Data TBD



#### Effects of medical history, interventions and background on stigma

PART 2	Model 1	Model 2	Model 3	Model 4
Education	Data TBD	Data TBD	Data TBD	Data TBD
Housing status	Data TBD	Data TBD	Data TBD	Data TBD
Relationship status	Data TBD	Data TBD	Data TBD	Data TBD
Insurance coverage	Data TBD	Data TBD	Data TBD	Data TBD
Acculturation	Data TBD	Data TBD	Data TBD	Data TBD
Age	Data TBD	Data TBD	Data TBD	Data TBD
F-model	Data TBD	Data TBD	Data TBD	Data TBD
R-model	Data TBD	Data TBD	Data TBD	Data TBD
Significance, model	Data TBD	Data TBD	Data TBD	Data TBD



# Questions?





# Transformation to a Trans-Centric Clinic: Improving access to HIV prevention and care

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# **Learning Objectives**

- Learn the impact of Transgender Stigma
- List important elements to create a Trans-centric clinic and the Steps to HIV Status Neutral Clinic
- Describe the elements for the Engagement and Empowerment Program and the priorities from Trans communities to access medical care.
- Recognize elements to increase the visibility and impact of HIV positive transgender in your clinic.



### Centro Ararat, Inc

**Centro Ararat, Inc.,** is a non-profit private, institution with a mission to provide access to comprehensive community-based primary care, mental health care, preventive healthcare and social services for diverse populations in underserved communities throughout Puerto Rico. Founded in Ponce, Puerto Rico in 2001.

#### Programs:

- RWHAP Part A, B, C & F (SPNS) Provider
- RWHAP Part C funded since 2014
- 4 Primary Care Clinics, 2 Special Care Clinics, 2 Pharmacies (340B)





# CENTRO ARARAT, INC.





- Research has shown that transgender women (TW) face higher rates of HIV infection than non transgender people.<sup>1</sup>
- African American TW face higher rates of HIV infection than those of other races and ethnicities.<sup>2</sup>
- 2015 survey of over 27,000 Transgender (Trans) people in USA, almost 1/4 reported that at some point in the past year they needed health care, but did not seek it due to fear of discrimination for being Trans.<sup>3</sup>
- The needs of the population are categorized in two groups:
  - Medical
  - Supportive Services



# Transgender Stigma in PR

- Legislation to protect members of Puerto Rico's LGBT community was first passed in 2014.
  - Compliance with the Supreme Court decision forced the state government to address matters related to change of name and gender in legal documents, but the process is cumbersome and expensive.
  - The novelty of the LGBT-oriented legislation in Puerto Rico has not granted enough time for the full implementation.



# Transgender Stigma in PR

- Adequate access to legal hormonal therapy
  - Regulations set forth by the Puerto Rico Insurance Commissioner do not specifically address the need for Transwomen.
  - Health insurance policies are not designed to facilitate the transition among Transwomen.
  - Review of policies and procedures to improve access to insurance and to reduce health care disparities for Transwomen in Puerto Rico is needed.



Definition= a social process of labeling, stereotyping, and rejecting human differences as a form of social control

- Individual-feelings people hold about themselves or their beliefs they perceive others to hold about them that may shape future behavior such as anticipation and avoidance of discrimination
- Interpersonal-direct or enacted forms such as verbal harassment, physical violence, and sexual assault due to gender identity, expression, or a diagnosis (HIV)
- Structural-the social norms and institutional policies that constrain access to resources



How stigma is presented?

- Attitudes that can lead to rejection by relatives, friends, and the society in general
- Stigma and discrimination is closely linked
- Stigma (negative beliefs)
- Discrimination (unfairly treatment)

How common, is hard to know

- Lack of trans visibility
- Poor documentation of Sexual Orientation, and Gender Identity. (No SOGI)
- Unrecognized, social tolerability, and underdiagnoses affect the actual commonness of stigma





#### Stigma consequences (Part 1)

- Affect income, to get and/or keep a job
  - Lack of legal protection leads to unemployment
  - The National Transgender Discrimination Survey (NTDS)<sup>4</sup>
    - 15% of respondents were living in severe poverty, (<\$10,000/year)</li>
    - 34% Black , 28 % Latina/o respondents reporting severe poverty.
  - As a way to meet every day necessities some transwomen engage in sex for commodities



#### Stigma consequences (Part 1)

- Affect ability to get and keep a place for living
  - 1/5 transgender individuals have experienced homelessness at some point.
  - 20-40% of the more than 1.6 million homeless youth are from the LGBT community.
  - Housing and food security rank high. 5
  - Poor health outcomes among WLWH
    - Lack of storage place for their medications
    - Lack of access to nutritional valued food



Stigma consequences (Part 2)

- Affect ability to get and keep health insurance
- Directly affect mental health and coping skills (risky behaviors, suicide attempt, and exposure to traumatic events)
- Affect ability to have and maintain long-term relationships
- Make it harder for the person to be open about sexual orientation, which can increase stress, limit social support, and negatively affect health



How to overcome stigma?

- Social support (family, friends, and community)
- Counseling/therapy
- Encourage respect and confidentiality
- Identify safe spaces
- Availability of a trans-centric setting
- Trauma-informed care
- Cultural sensibility
- Cultural humility



#### **TRANS-centric Clinic**

- Need Assessment
  - Quality clinical care
  - Medical providers that are affordable and Trans-sensitive
- Strategy
  - Design and implement an innovative clinical settings focused on Transgender priorities, continuous improvement, prevention, linkage to care and continuum in care under the umbrella of primary care and quality of life.



#### TRANS-centric Clinic: Community Partners

- A mapping of the community was conducted, scouting sites for social gatherings, and/or agencies that provide services to the target population (housing, legal, job readiness, advocates, free services)
- In order to establish a solid relationship with a community partner, a meeting
  was scheduled for staff to discuss the benefits of the collaboration with intent to
  help the community.
- Develop a memorandum of agreement.
- Put in place a policy and procedures for referral services.



# **TRANS-centric Clinic - Accessibility**

- Financial- free, low-cost, or on a sliding scale.
- Time- flexible schedule, including evening and weekend hours.
- Location- responsive to community needs. (eg. near public transportation)
- Service- "one stop shop"
- Family inclusion (welcome chosen family)
- Trained staff



# TRANS-centric Clinic - Training

- Transgender medicine
- Trauma informed care
- Harmed reduction strategies (HIV prevention)
- Biopsychosocial HIV care



# TRANS-centric Clinic- Staff

- Supporting Staff
  - Clinic Coordinator
  - Trans Project Coordinator
  - Case Manager
  - Retention Specialist
  - Security Services
  - Data Manager





# TRANS-centric Clinic - Clinical Staff

#### *In-site*

- 2 part time physician with vast knowledge in Trans healthcare
- 1 clinical nurse
- 1 medical case manager
- 2 retention and adherence specialist
- 1 part time psychologist
- 1 part time nutritionist
- 1 navigator
- 1 part time health educator

#### Off-site

Trans-friendly directory



# TRANS-centric Clinic - Services

- Primary care services include
  - HIV care
  - Non HIV Trans Care
  - ART adherence
  - Dental
  - Nutrition
  - Hormone therapy
  - PrEP Service
  - STI diagnosis and treatment
- Mental Health Services
- Pharmacy Services
- Support Services







Hormone therapy



# **TRANS-centric Clinic - Services**

- Supportive services include:
  - Assistance with name change, gender marker
  - Assistance with online or in-person application for benefits such as SSI, cash and food vouchers
  - Accompanying patients to appointments, including surgical, legal, and housing appointments
  - Referral to trans-sensitive shelters and housing specialists
  - Referrals to comprehensive legal services
  - Transportation



# TRANS-centric Clinic – Start-up

- Outreach non-traditional events
  - Work sex for commodities areas, handing out safer sex packages that include program materials, condoms, and lubricants.
  - Health education throughout social media networks.
  - Private messaging to remind patients of appointments and upcoming events.

#### Recruitment

- Special events activities for enrollment.
- Peers receive small incentives for bringing people from their social networks.

#### Retention

- Supportive services is a key component.
- Focus on individual's priorities.
- Safe space



# TRANS-centric Clinic -Sustainability

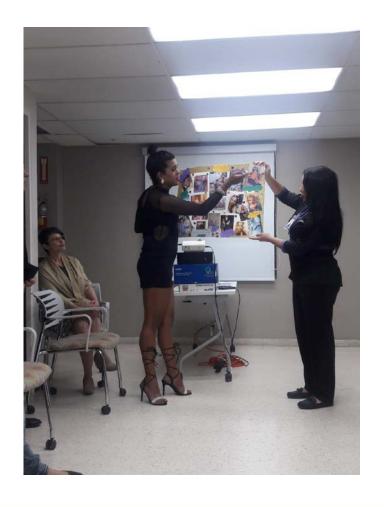
- Few programs provide grants specific for the Transgender population
  - AIDS United www.aidsunited.org
  - MAC
  - Elton John Foundation
- Ryan White Funds
  - All services related to HIV (+) clients (PNC 16-02)
  - "Target HIV Testing" and "High Risk Education" (EIS)
  - https://www.targethiv.org/library/models-leveraging-rwhap-support-prepservices
- CDC and Prevention Funds
  - Local Health Department
- Third Party Billing
- Fundraisings and Donations



- The "Four Pillars" of *Translucent Clinic* are building blocks that prepare participants, in a structured manner, to address issues of self-esteem and self-awareness.
- These elements are critical to prepare a participant to succeed in the engagement and adherence of a treatment plan.
- Many participants' priorities are related to gender affirming topics, before they are interested and committed to managing HIV/STIs.



- The Four Pillars are:
  - My Intimacy
  - My Militancy
  - My House in Order
  - Healthy Life, My Divine Body!





#### My intimacy

- How do I relate to myself?
- Self-esteem and intimacy
- Circles that affect me
- Reconciling with myself



#### My Militancy

- Where do I belong?
- My community
- My history
- My space





#### My House in Order

- Eliminating barriers to obtain physical and mental health services
- Legal documents aligned with my identity
- Facing my future: "Back to school, back to work"
- Barrier-free citizenship: Full access to services



#### Healthy Life, My Divine Body!

- Hormones and my body
- Sexually transmitted infections, testing & prevention
- HIV, testing & prevention
- PrEP & PEP





	YEAR 1: 2017	YEAR 2: 2018
Completed Workshops	64	48
LTFU	7	6
FHT	45	27
TLWH	7	11
PrEP	10	5
STIs Evaluation:		
Chlamydia	57	31
Gonorrhea	57	31
Syphilis	57	31



- Vision: Getting to zero new HIV infections
- Impact: A significant and rapid reduction in new HIV infections
- Outcomes:
  - Suppress viral load among TLWH
  - Increase use of PrEP among Trans at increased risk for HIV infection



Structurally, *Translucent* Clinic has operated in a coordinated fashion with CA's HIV Program at Centro Ararat San Juan.

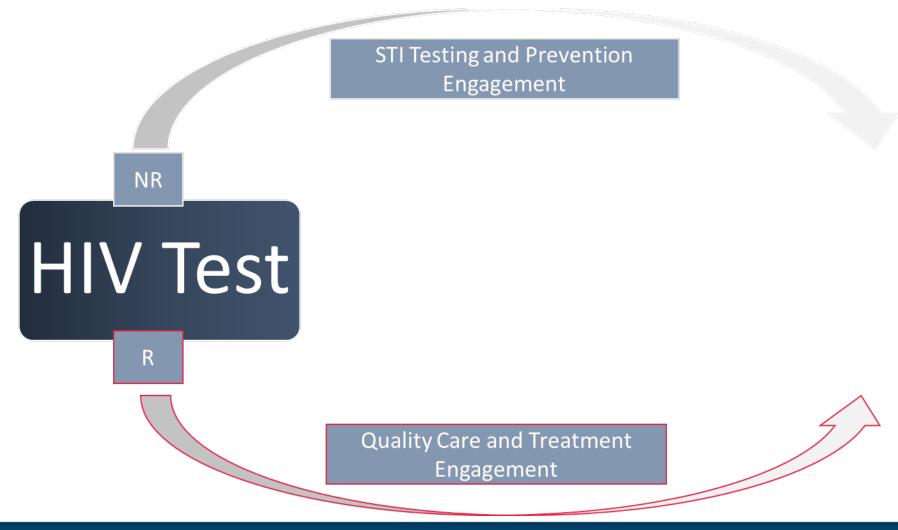
- Once ready, participants are encouraged to engage in a testing and referral process.
  - To protect every participant's privacy, the tests are offered for a whole range of health screenings, including hormonal levels and HIV and STIs.
  - CA ensures that no one is stigmatized for getting a particular type of test, and since hormonal therapy is offered as a "graduation present" to all participants who complete the educational processes.
- Translucent participants who test positive for HIV are immediately referred to our HIV program.
  - The privacy of those who test HIV (+) can also be maintained as they engage in ART in combination with their hormone therapy.



Structurally, *Translucent* Clinic has operated in a coordinated fashion with CA's HIV Program at Centro Ararat San Juan.

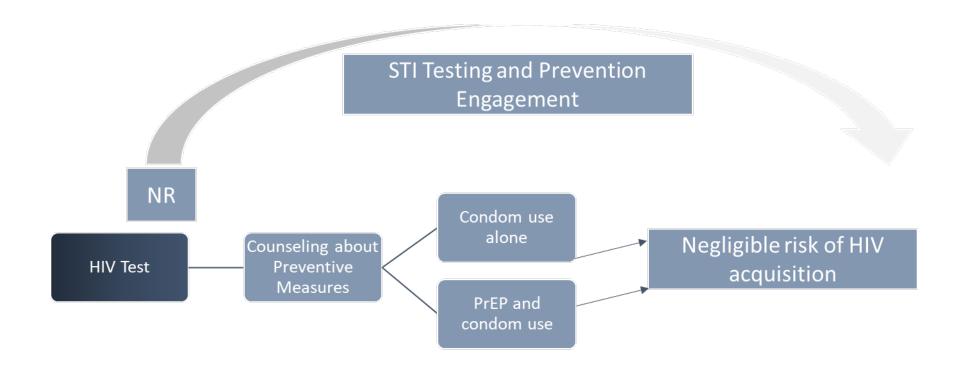
- Translucent participants who test negative for HIV are referred to CA's PrEP Program and all participants are also offered mental health and nutrition services.
- Medications for ART, PrEP, hormone therapy and for any other comorbidity are dispensed from the CA Pharmacy.
- The *Translucent* Case Manager is also trained to identify support needs that the patient may have and which may compromise their ability to access or to adhere to their clinical care and therapy.





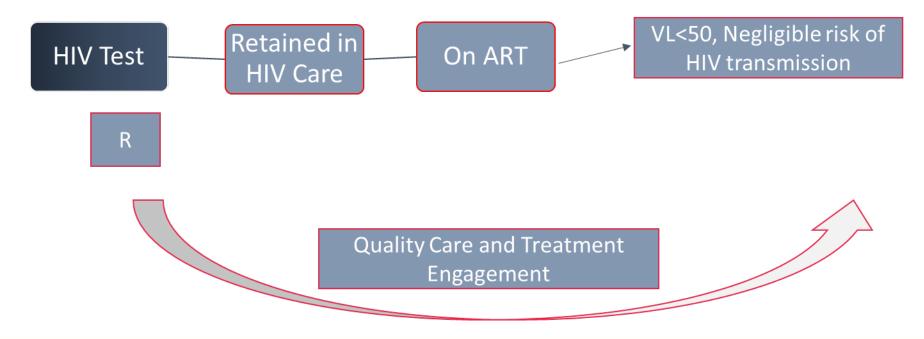






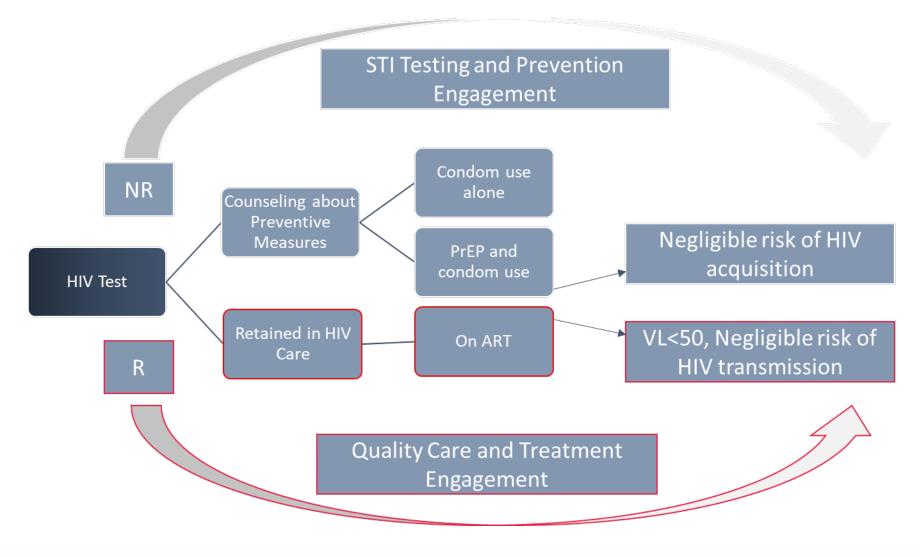
















# **Long-Term outcomes**

- Improved quality of life
- Improved health outcomes
- Sustained patient engagement on HIV prevention services
- Sustained patient engagement on HIV primary care
- Increase the visibility and impact of TLWH in the larger community of HIV advocacy
- Improve the delivery of health services for members of the community not linked to Centro Ararat.



# **TRANS-centric Best Practices(1)**

- Due to the disproportionate impact of HIV among the transgender community, particularly among transgender women of color, it is critical that clinics and support services are welcoming, inclusive and competent in serving this population.
  - The MIPA principles must be held up as inclusive of trans communities and serve as a tool in designing and offering care and services.



MIPA - Meaningful Involvement of People with HIV/AIDS



# **TRANS-centric Best Practices(2)**

- Maximize trans inclusion and leadership in all aspects of funding initiatives including planning, review of applications, and grantee selection.
  - Trans representation should reflect the diversity of the trans communities (trans women, trans men, and non-binary, and/or gender-expansive)
- Implement low-barrier, seamless health care and linkage services





# **TRANS-centric Best Practices(3)**

- Health care organizations should include trans staff members
  - People can better relate to a provider who is like them, particularly trans.
- Providers and health care organizations should affirm and respect all clients' gender identity
  - When trans people are treated respectfully, regardless of gender expression, they are more likely to stay engaged and remain in medical care.





# TRANS-centric Best Practices(4) At the Clinic:

- Preferred gender pronouns:
  - ■He/Him
  - □She/Her
  - ■They/Them
  - Other:



The prejudicial treatment or considerable of a person, racial group, minority, based on category rather than indicated and the grounds of race, sex, or account on the grounds of race, sex, or account of the grounds o





# **TRANS-centric Best Practices(5)**

 Health care providers must take responsibility for educating themselves and developing their capacity to serve trans clients.



 Health care organizations should engage in continuous evaluation of trans clients' satisfaction with health care programs.





# **TRANS-centric Best Practices(6)**

- Appropriate health care services must be provided to all trans clients who need them.
  - Adhere to Culturally and Linguistically Appropriate Services (CLAS Standards§)
  - Providers must facilitate appropriate health care procedures and screenings for patients based on their anatomy. (Pelvic Exam, P/S, prostate & breast exams)



§National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care



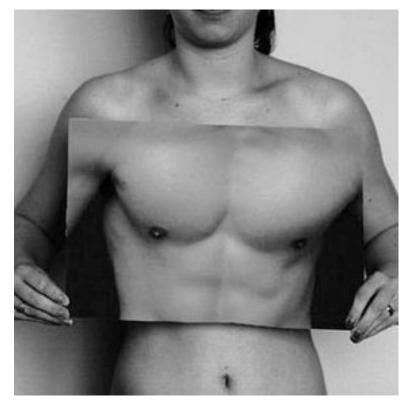
# **TRANS-centric Best Practices(6)**

Appropriate health care services must be provided to all trans clients who need

them.

Gatekeeping model Vs Informed Consent model

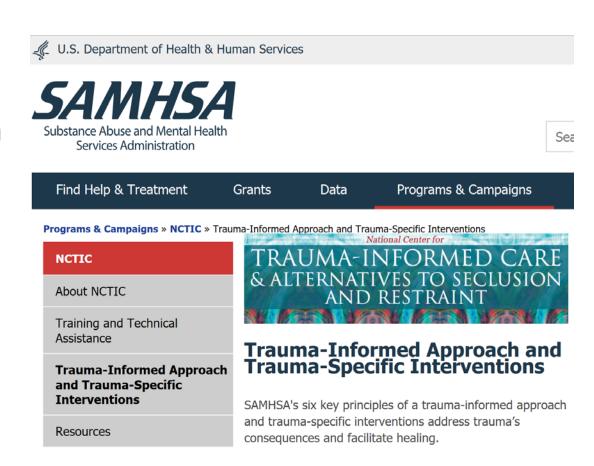
Providers should move toward an Informed Consent model





# **TRANS-centric Best Practices(7)**

- Services provided to trans clients should be traumainformed in both their approach and implementation.
  - Service providers should follow the Substance Abuse and Mental Health Services Administration (SAMHSA)





#### **Lessons Learned**

- Trans people face disproportionate levels of discrimination and violence. This
  manifests in a variety of ways including lack of employment and housing
  opportunities.
- Physical intimidation and violence can make it difficult to leave one's home to seek out and receive services.
- Trans people are strong and resilient.
- Community dialogue is fundamental to the response to HIV.
- Organizations must understand the needs and respond to the concerns, questions, and doubts that are generated in the target community



### **Lessons Learned**

- Part of our commitment to the execution of the project was community empowerment, so participants were able to become their own advocates and were able to disseminate and replicate the information to the rest of their peers in the community.
- It is important to create more programs that are trans-specific, trans-inclusive and trans-directed.
- "One-stop shop" is a key element to retain and engage people in a consistent level of preventive and primary care.



# Thanks to:

# AIDS









#### References

- https://www.aidsunited.org/resources/meaningful-involvement-of-people-withhivaids-mipa
- Gender Transition and Medicine Gatekeeper vs. Informed Consent Models by Michaella Kinloch
- https://www.samhsa.gov/nctic/trauma-interventions



# Questions?





#### **Contact Information**

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