

# Decreasing HIV Stigma by Effectively Communicating the Message of U=U

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Prevention Access Campaign



## Learning Objectives

### By successfully completing this session:

- 1. Participants will be able to define Undetectable = Untransmittable in a manner that is understandable by the masses.
  - Define (U=U) Undetectable = Untransmittable
  - **Explain** the science and research behind the movement
  - Demonstrate relevant methods of promoting U=U
- 2. Participants will be able to promote an environment that decreases stigma and encourages positive HIV messaging.
  - Increase awareness about the existence of HIV stigma
  - Introduce ways to alleviate negative messaging
  - Build strong advocacy and activism systems to provide support for the cause
- 3. Participants will be able to employ newly learned principles in various environments.
  - Discuss the importance of increasing community access to the U=U message
  - \* Advocate to decrease known barriers to U=U access
  - Demonstrate best practices for garnering support among multiple audiences



### **Disclosures**

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## AETC Program National Centers and HIV Curriculum

- National Coordinating Resource Center serves as the central web –based repository for AETC
  Program training and capacity building resources; its website includes a free virtual library with training
  and technical assistance materials, a program directory, and a calendar of trainings and other events.
  Learn more: <a href="https://aidsetc.org/">https://aidsetc.org/</a>
- National Clinical Consultation Center provides free, peer-to-peer, expert advice for health professionals on HIV prevention, care, and treatment and related topics. Learn more: <a href="https://nccc/ucsf.edu">https://nccc/ucsf.edu</a>
- National HIV Curriculum provides ongoing, up –to-date HIV training and information for health
  professionals through a free, web –based curriculum; also provides free CME credits, CNE contact hours,
  CE contact hours, and maintenance of certification credits. Learn more: www.hiv.uw.edu

# Did You Know?



PAC's public health initiative to leverage the U=U campaign to increase viral suppression and quality of life among the estimated 400,000 people living with HIV in the U.S. who are not virally suppressed.

### Zundra Bateaste-Sutton





## she/her/hers







# Prevention Access Campaign

Our Shared Vision: All people w/ HIV will love and live free of HIV stigma and fear of transmitting HIV.

Our Goal: To change the HIV risk narrative worldwide.

Objectives of this training: Increase knowledge, tools, and skills for effective advocacy to achieve our vision & goal on our journey to ending the epidemic.





UNDETECTABLE

UNTRANSMITTABLE



NIET DETECTEERBAAR NIET OVERDRAAGBAAR

**UNINFECTIOUS** UNDETECTABLE

NDETECTABL

### are the solution

Taking HIV medication daily suppresses the virus and means you can't pass it to others.

nam aidsm

The scientific evider

#Uequal



ACT UP DUBLIN

SCIENCE=HEALIH

#UequalsU #ScienceNotStigma

VIHJ بالعلاج

مايتـراش = مايتعدّاش

OPLE ON EFFECTIVE

IV TREATMENT



I CAN'T

PASS ON HIV.

People on effective HIV



### UNDETECTABLE = UNTRANSMITTABLE НЕДЕТЕКТАБИЛНО = НЕПРЕНОСЛИВО



### San Francisco AIDS Foundation supports



The science is clear: People living with HIV, who are on effective treatment do not transmit HIV to









Здружение за поддршка на луѓето живеат со ХИВ -

sexual partners.

Podporujeme!

**Around the World** 

The National HIV Nurses Association is proud to

No more scaremongering

People on effective HIV treatment can't pass on the virus.



治療によって血液中にHIVが見つからないレベル Prevention A GONEROUS PROPERTY LEE



検出限界以下は感染しない

HIVはうつることはありません。

#UequalsU #検出限界以下は感染しない

KHÔNG PHÁT HIÊN



### WHAT IS U=U?

# **Undetectable = Untransmittable**

People living with HIV who are on treatment and have an undetectable (<200 copies/mL) **CANNOT** transmit HIV to their sexual partners.





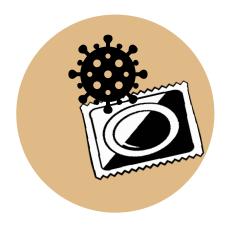
# U=U GUIDELINES







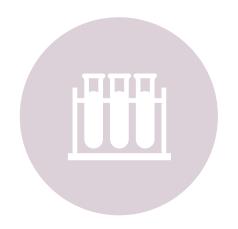
**⇒** SEX



**⊝HIV** 

### **U=U GUIDELINES**







TREATMENT

**L**ABS

CARE





# How do we know U=U?

Summary of Recent Evidence for Undetectable=Untransmittable (U=U)

					1	
				<u>Nt</u>	umber of New H	V Infections
			Number of			Phylogenetically Linked When HIV+
			Condomless		Phylogenet call	
Study	Enrolled Sample	Study Design	Sex Acts	Total	Linked	Virally Suppressed
HPTN 052	1,763 serodifferent couples	2-arm trial with	-	78	46	0
Cohen et al., 2016	98% male-female couples	HIV+ partner		<ul> <li>19 in early-</li> </ul>	• 3 in early-	
		randomized to early		ART group	ART group	
		or delayed ART		<ul> <li>59 in delayed-</li> </ul>	to the second transfer of the second transfer	
				ART group	ART group	
PARTNER1	1,166 serodifferent couples	Observational	55,193	11	0	0
Rodger et al., 2016	888 in analytic subset     62% male-female couples	study	<ul> <li>34,214 among male-female couples</li> <li>20,979 among male-male couples</li> </ul>			
Opposites Attract	358 serodifferent male-male	Observational	12,447	3	0	0
NAME OF BUILDINGS	couples	study	• counted when		405	000 11
	Sex	withou	ITHICONG PrEP	oms	> 125,	000 times
	972 serodifferent male-male couples	Observational study	76,991	15	0	0
	• 783 in analytic subset	Judy				



# WHY IS U=U A GAME CHANGER?

- Quality of life for People with HIV:
   Transforms social, sexual, and reproductive lives
- HIV Stigma: Dismantles HIV stigma on the individual, community, clinical, and public policy levels
- Treatment Goals: Reduces anxiety associated with HIV testing and adds an incentive to start and stay on treatment and in care
- Universal Access: Provides a strong public health rationale to increase access and eliminate barriers to treatment, care, and diagnostics. (The Third U = Universal)







# Kody (Madison) & Dr. Cooks

Kody is a 28-year-old MTF person living with HIV for the last 5 years. Kody, whose preferred name is Madison has not been engaged in care consistently and is reengaging in care after 2 years. Madison is having her Ryan White medical visit with Dr. Cooks.



**Dr. Cooks:** Kody, how are you today, Sir? I see that you've been positive for 5 years now. Why were you not in care and on meds? Don't you know that if you don't take your meds then you'll infect others with HIV? You could be out here killing people.

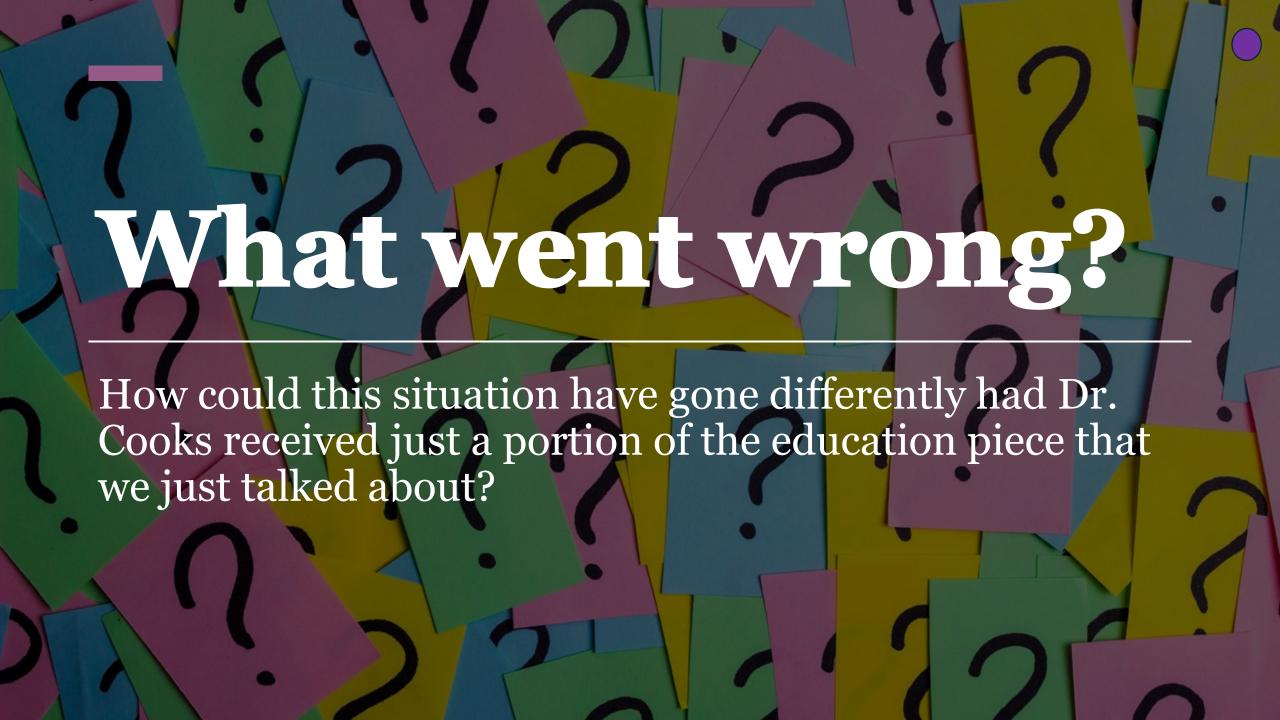
**Madison:** First, My name is Madison, and excuse me?! I don't appreciate your approach at all. I was not consistent in my care because my Aunt used to work here at the only clinic within 100 miles, and I did not need her knowing my business. I want to be in care now, I heard about U=U but now I'm good on this. I'm out!"

(Dr. Cooks mumbles to herself)

Dr. Cooks: He'll be back!







## Providers must inform patients about U=U

It is inexcusable for providers to withhold the U=U message from any patient living with HIV. There is no medical justification for it.

Conveying benefits and risks surrounding any treatment is fundamental to patients' decision-making, and this HIV treatment benefit should be no exception.

Educating patients about U=U is aligned with treatment goals: optimal adherence, viral suppression, treatment satisfaction

Educating all patients about U=U is crucial to maximizing the wellbeing of PLWH.



### Providers should discuss U=U with all patients living with HIV (1)



As scientific knowledge surrounding the link between guilt surrounding potential transmission, and enabling Loncet HIV 2019 HIV viral suppression and transmission risk evolves, sex without fear. Beyond direct benefits, educating Published Online messaging to patients must be updated accordingly. patients about U=U could indirectly reduce community http://dx.doi.org/10.1016/ Presenting the results of the multisite, observational viral load by encouraging HIV medication adherence \$2352-3018(19)30030-X PARTNER2 study at the 22nd International AIDS and consequent viral suppression, supporting public

Sarah Calabrese, PhD Dr. Kenneth Mayer

February 2019

### Build Networks

- Reach out to Community
- Garner Support (Doctors, Organizations, Businesses, Legislators)
- Collaborate

### Increase Testing

- Make Available
- Explain Importance
- Ensure Privacy

### Reduce Stigma

- Recognize Stigma
- Identify the Cause
- Replace with Facts



# HIV STIGMA

is a <u>public health</u> <u>emergency</u> is an <u>immediate</u> and <u>effective</u> response.





### MSDH –EHE Mississippi State Department of Health – Ending the HIV Epidemic

The plan sets ambitious goals – achieving a 75% decrease in new HIV infections by 2025 and seeing at least a 90% reduction by 2030.

### The four key strategies are:

- Diagnose all people with HIV as early as possible
- Treat people with HIV rapidly and effectively to reach sustained viral suppression
- Prevent new HIV transmissions by using proven interventions, including pre-exposure prophylaxis (PrEP) and syringe services programs (SSPs)
- Respond quickly to potential HIV outbreaks to get needed prevention and treatment services to people who need them

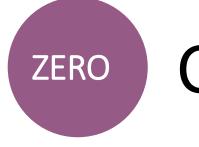
### The four additional strategies are:

- Increase access to effective and comprehensive care across the state
- Decrease stigma and provide life-affirming messaging and care
- Identify, address, and reduce health disparities
- Increase MSDH capacity to develop new, innovative partnerships that are responsive to the needs of the individuals most at risk for acquiring HIV in MS





## COMMUNICATING U=U



Clear



Consistent



Confident



Conscious



# Le'Andre, Nurse Sheila, & Dr. Cooks

Le'Andre is a 25-year-old Afro-American man from Carthage, MS, who was recently living in Atlanta, GA. He has been living with HIV for 2 years. He is Undetectable, knows U=U and is trying to establish care in MS.



**Nurse Sheila:** Hi Le'Andre! Its good to see you, I'm your cousin Keisha's good friend... Hold on I will be right back. (The Nurse goes in the hallway and calls Keisha.)

**Keisha:** HELLO!

**Nurse Sheila:** Girl, your cousin up here at the Clinic. I told y'all he had that package! I gotta go tho, here comes Dr. Simms.

**Dr. Simms:** Hey Nurse Shelia, I heard you on the phone. What's going on with this young man?

Nurse Sheila: Well, Le'Andre in there and you know I know his cousin...

(Just then Le'Andre walks from the room.)

**Le'Andre:** Yeah, I heard you, too, and my cousin already texted my Mama and Aunts. THANKS! They didn't know. I'm ruined now!







## James & Steven

James is a 24-year-old young man from Hattiesburg, MS who tested positive for HIV one year ago. James has already achieved an Undetectable viral load. James has been dating Steven for 4 months and has not disclosed his HIV status.



Steven: Baby, its bout that time we go on and take it to the next level. Let me come spend the night with you.

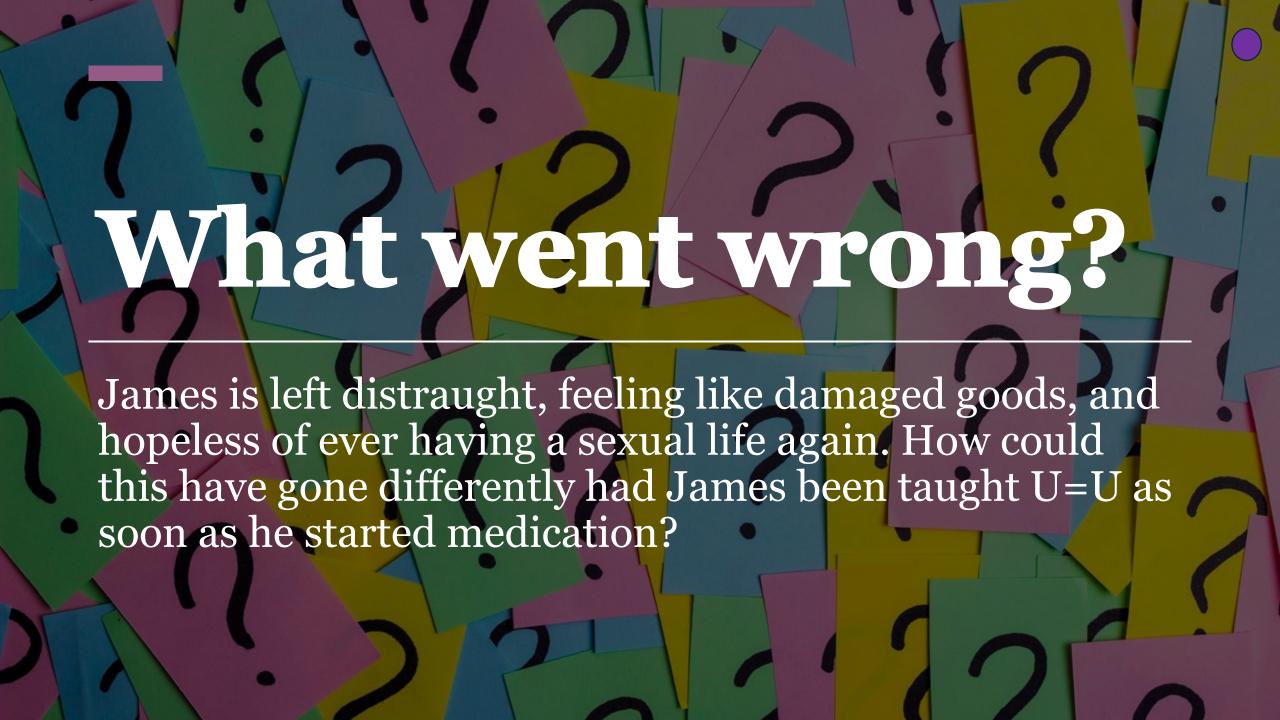
**James:** Steven, I really want that, but we need to talk first before that happens.

**Steven:** Wait, don't even tell me. You got them AIDS? ...Don't even waste your time, I can't be getting caught up like that. Maaan, I should've known that you sleep around.

**James:** Excuse me!? I AM HIV Positive, but I am Undetectable and cannot transmit HIV. But what does that have to do with sleeping around?

**Steven:** Dude, all of yall lie and catch AIDS from being in the streets. Lose my number.





# Let's choose facts over fear!

Recognize

cognitive

dissonance



# Recognize Separate

Separate feelings from facts

### Consider

Consider the positive and negative impacts

### Borrow

Borrow confidence from the experts

# Advocacy

The Voice

The Face

The Driving Force



Meet them where they are...

# Advocism strategies

**Identify targets**: Identify who you need to influence that has not yet communicated U=U and are opportunities to become U=U partners. This might be your health ministry, ASO, leaders, media and other targets that have an influence both within and outside the field.

**Build coalitions**: Look at the influencers in your community including individual leaders, researchers, healthcare providers and public health officials and already established networks that you can engage as partners in changing the risk narrative and collaborating on your approaches to the targets. Fortunately, many of your targets will become partners.

**Promote on social media**: Social media, primarily Twitter, has been the way the campaign has expanded and shows our force as a community. Join Twitter and follow the campaign and #UequalsU hashtag. This is important because agencies monitor PAC and U=U to get a sense of how organized and influential the movement is.





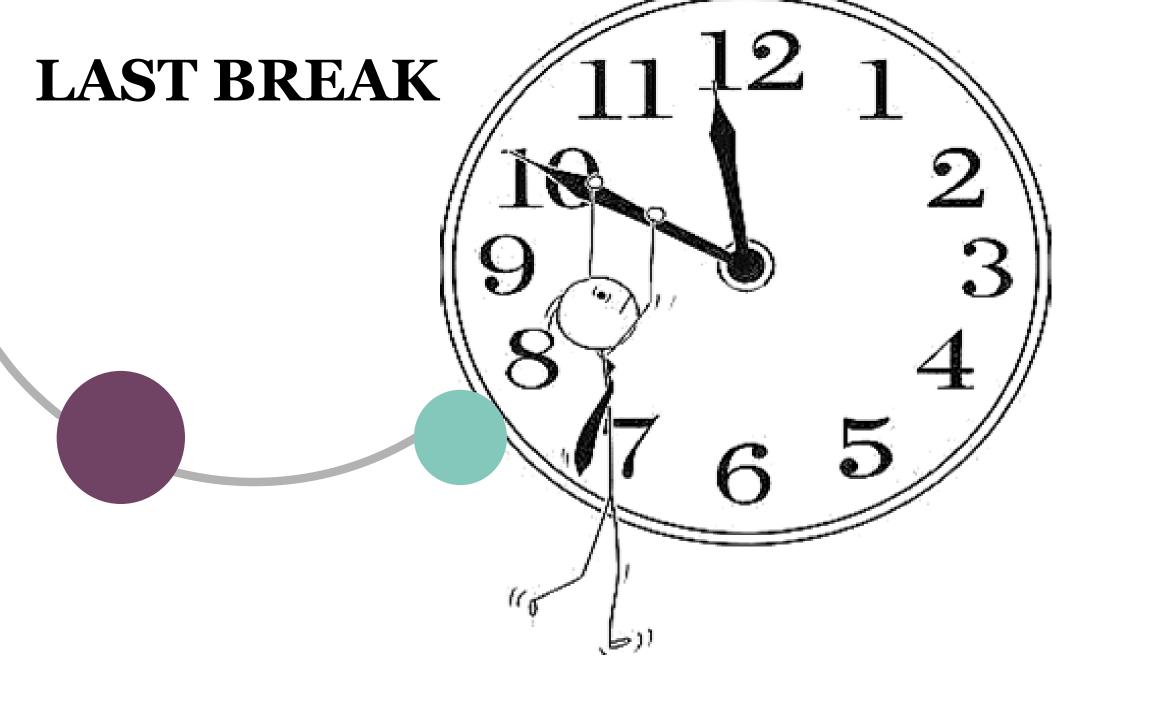
# Advocism strategies

**Engage targets**: Ways to move targets toward communicating U=U might include:

- **Individual meetings** ensure the messengers at these meetings are credible and culturally appropriate. Identify influencers who can advocate behind the scenes as well.
- **U=U specific conferences** convene a gathering of influencers for a U=U conference or forum. Ensure that your targets are invited. Depending on your targets, you might invite global experts in U=U science to speak. Contact PAC for examples of how other conferences have been successful.
- **U=U integration into conferences** ensure U=U is a part of the conferences that your targets typically attend.
- **Sharing stories** appeal to emotion to help them to recognize the importance of U=U through stories of suffering from HIV stigma as well as the great joy that U=U brings and the ways U=U supports personal and public health goals.
- Social media pressure appeal to their reputation with appropriate calls to action







# Jonathan, Michelle, & Dr. Hassan

Jonathan and Michelle have been a couple for 3 years. Jonathan is a cisgender male, Michelle is a transgender female. Michelle has been living with HIV for over 2 years, and has been adherent to her medication but does not know anything about U=U. Jonathan is HIV negative and wants to remain that way. They schedule a visit to Michelle's HIV provider, Dr. Hassan.

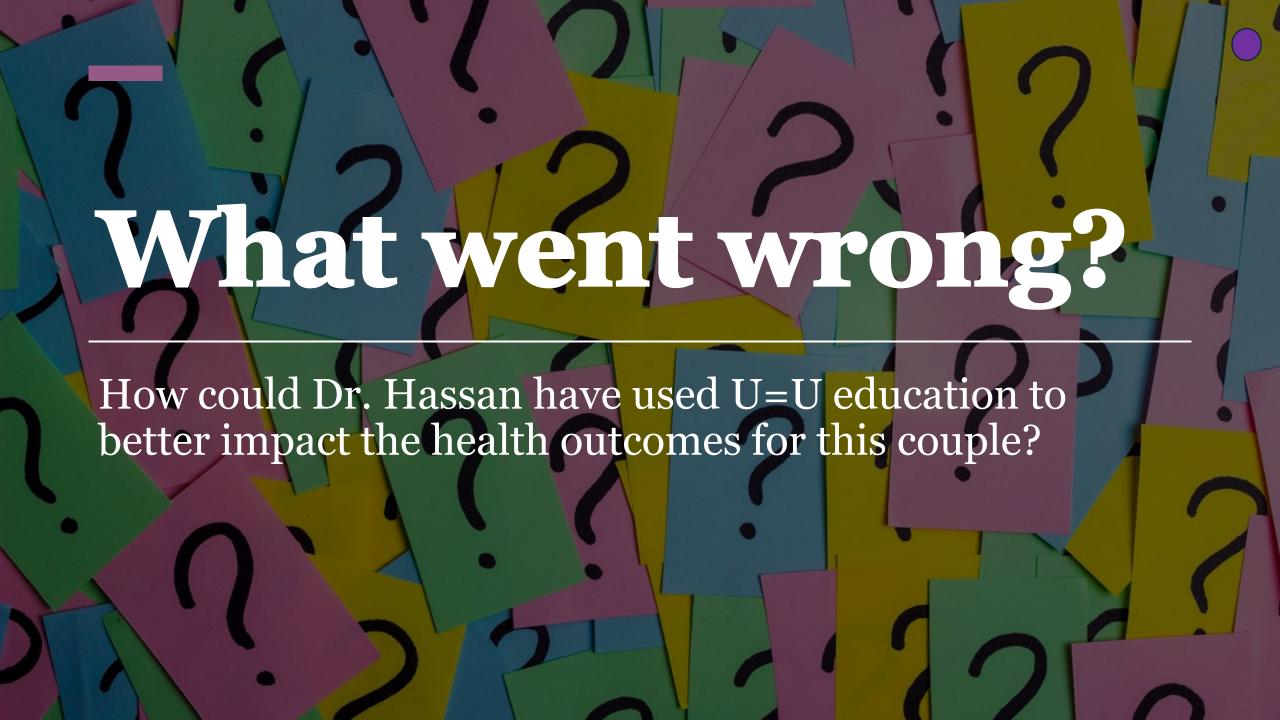
**Dr. Hassan:** Hi Michelle & Jonathan, what brings you two in today?

**Michelle:** Well we're here because Jonathan doesn't want to use condoms anymore but he's scared about catching HIV."

**Dr. Hassan:** Well he has a right to be nervous, Michelle. You are a trans who has HIV. And Jonathan is at an even bigger risk because you're a top. He needs to be on PrEP ASAP.

Michelle: (Breathe hard)





### **EDUCATION/OUTREACH**

- **PLWHIV**
- **№** Community Members
- Political Figures
- **S** Church Members
- **S** Family/Friends
- **Schoolmates**
- **M** Colleagues
- **X** Youth

- **№** Health Departments
- Community Based
  Organizations
- Physicians & Staff
- **S** Clinics
- Networks

### **CONNECTION TO SERVICES**

Identify Population
Identify Needed Services
Identify Providers of Needed Services
Reach Out to Gain Support of the Providers
Connect Population with Services

### **COMMUNITY MOBILIZATION**

The goal of community mobilization is to get together as many members of the community as possible to create, implement, and monitor initiatives/programs.





# Tying It All Together





# Doing Your Part

- Use the public health strategy of U=U to increase access and remove barriers to information, treatment and care. (Reduce Transmission)
- Have a conversation with those living with HIV or who are vulnerable to HIV at every opportunity. (Propose U=U)
- Make U=U central to speeches/ events (Increase Education)



PEOPLE WHO HAD A CONVERSATION ABOUT U=U WITH THEIR HEALTHCARE PROVIDER

MORE LIKELY TO REPORT VIRAL SUPPRESSION



## **RECAP**

### We Discussed

- The definition of U=U
- U=U Science
- Methods to promote U=U
- Awareness of HIV Stigma
- Ways to alleviate negative messaging
- Growing in your advocacy & activism
- Increasing community access to U=U
- How to decrease known barriers
- Demonstrating best practices

# The Road Map

- Identify the Need
- Increase Access to the Message
- Find Your Voice/ Help Others Find Theirs
- Implement A Plan of Action

Change the World! End the HIV Epidemic!



## References

- 1. WHO. Viral suppression for HIV treatment success and prevention of sexual transmission of HIV. https://www.who.int/hiv/mediacentre/news/viral-supression-hiv-transmission/en/ Accessed February 28, 2021. 2. WHO Joint Statement Ministry of Public Health of Thailand, WHO, and UNAIDS. <a href="https://unaids-ap.org/joint-statement-ministry-of-public-health-of-thailand-world-health-organization-who-and-joint-united-nations-programme-on-hiv-aids-unaids/Accessed February 28, 2021.">https://unaids-ap.org/joint-statement-ministry-of-public-health-of-thailand-world-health-organization-who-and-joint-united-nations-programme-on-hiv-aids-unaids/Accessed February 28, 2021.</a>
- 1. PEPFAR. PEPFAR 2021 Country and Regional Operational Plan (COP/ROP) Guidance for all PEPFAR Countries.
   <a href="https://www.state.gov/wp-content/uploads/2020/12/PEPFAR-COP21-Guidance-Final.pdf">https://www.state.gov/wp-content/uploads/2020/12/PEPFAR-COP21-Guidance-Final.pdf</a>. Page 336. Accessed February 28, 2021 2. Page 338
- 1. CDC Global. Undetectable = Untransmittable Strategic Toolkit. <a href="https://58b1608b-fe15-46bb-818a-cd15168c0910.filesusr.com/ugd/de0404">https://58b1608b-fe15-46bb-818a-cd15168c0910.filesusr.com/ugd/de0404</a> dc7f983a5b33410fbdaf62e84a192aa9.pdf Accessed February 28, 2021 Page 8; 2. Page 3; 3. Page 7





# THANK YOU

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