

U=U (Undetectable = Untransmittable) Storytelling Guide

Introduction

Project Background

According to the Centers for Disease Control & Prevention (CDC), “timely diagnosis of HIV and sustained antiretroviral treatment (ART) increase the quality of life for a person with HIV, and prevents the spread of the virus, and research shows that suppressing HIV to undetectable levels virtually eliminates transmission of the virus to sexual partners.”¹ Yet, a considerable proportion of healthcare professionals are still not educating patients about U=U (Undetectable = Untransmittable) despite emphatic endorsements by the scientific community.²

Primary Care Development Corporation (PCDC), and the New England AIDS Education and Training Center (NEAETC), collaborated on a storytelling project which features short videos portraying the interwoven stories of four women of color from diverse backgrounds, all long-term survivors with HIV. PCDC and NEAETC developed the videos to inform healthcare professionals about the importance of what U=U means to people with HIV. Each video demonstrates strength, power, resilience, and the importance of honest communication between providers and clients.

Intended Use(s)/Audience(s)

These particular videos are of use for healthcare and service providers that serve a large population of Black women. Black women have unique needs and lived experiences, as reflected in these stories.

Healthcare and Social Service Professionals (e.g., physicians, nurses, case managers, social workers, etc.)

Healthcare and Social Service Professionals have a unique role to play in a client’s ability to reach an undetectable HIV status. They have the technical knowledge and skills necessary to work with clients to create a care plan that works towards an undetectable status. However, it has been seen that even with all these skills, tools and knowledge, some clients may not fully grasp what U=U could mean for them. These videos strive to serve as a tool to bridge this gap. Hearing directly from these women who have been living and thriving with HIV and have experienced the impact of U=U messaging on a personal level may be that additional push that clients need to understand and possibly attain an undetectable status. Providers can engage with these videos by:

- Having the videos playing in the waiting room
(this also serves to normalize HIV and reduce stigma because everyone sees the videos)
- Selecting one story to catalyze a discussion with a client
- Using the videos as a supplement to employing peers (people with similar lived experiences).

Peers

Peers are in a unique position to have conversations about U=U with clients with HIV. They have some shared experiences navigating healthcare, facing stigma, and adjusting to a daily medication regimen. These videos provide additional support to discuss what U=U means to peers, and what it can mean to the clients they are working with. Peers can engage with these videos to:

- Introduce the concept of U=U
- Share stories that may better reflect the culture and experiences of their clients

The stories these women tell can bridge providers and clients. The videos can be used with a newly diagnosed client, or someone who has been living with HIV for decades. The reality of U=U that is shown in these videos demonstrates that a healthy life living with HIV is not only possible, but within reach.

Background on Storytellers

Dawn



Dawn Trotter, Co-Chair and Women's Concerns Coordinator for New York's Statewide Weekly Peer Check In, works as a Patient Adherence Specialist in an HIV clinic. Inspired to share and educate, Dawn is able to relate to patients and engage them through her own life experience, applying her passion to help peers maintain their healthcare, promote adherence toward viral suppression, improve patient experiences and ensure positive health outcomes. Some of the organizations that she is linked with are as follows: NY Links, CQII SPNS Aging with HIV ECHO Collaborative as a Content Expert, and Dawn was the 2nd Peer in New York State to be certified as a New York State Certified HIV Peer Worker. Dawn has also served the NYS AIDS Institute Consumer Advisory Board since 2014 & is a NYS Dept of Health HIV Stops with Me Spokesmodel.

Michelle



Michelle Lopez is a tireless advocate when it comes to Public Health among Black and Latinx communities. Michelle has worked in HIV and AIDS prevention and Health Care navigation, substance use services and peer initiatives. Michelle has over thirty years of experience being an educator, linkage to care and treatment access specialist for immigrants - particularly people migrating to NY and in need of care and services diagnosed with HIV. Michelle has served on the Board of Directors and contributed to policy development that impacts the lives of marginalized communities. Michelle is now focusing on research, looking at developing models and methods to have meaningful involvement of community individuals, and partnering with researchers to create better research designs that impact community needs.

Video Details

Dawn

Dawn is a healthcare advocate. This video can be a powerful tool for discussion with heterosexual women with HIV and women who have children. Video length: 6 minutes, 12 seconds. Click [here](#) to view.

Michelle

Michelle is an activist and advocate. She has experience navigating the healthcare system as an undocumented immigrant. She also discovered her status after the birth of her child, who is also living with HIV. This is an excellent video to generate conversation with bisexual women, Black women, women with several comorbidities (e.g., diabetes) or women immigrants. Video length: 6 minutes, 55 seconds. Click [here](#) to view.

Discussion Questions

Below are suggested discussion questions to help facilitate the use of the storytelling videos.

1. Before watching the video(s), ask the client, “What does U=U mean to you?”
2. After watching the video(s), “Has the meaning of U=U changed for you? If yes, how so?”
3. What are your thoughts/feelings after watching the video(s)?
4. What do you think about achieving an undetectable viral load? *Note that this should only be asked of clients that are medically capable of achieving an undetectable viral load.*
 - Why/why not?
 - What do you think is the best first step for you?

Key Takeaways



Undetectable can be attainable for almost everyone living with HIV.



U=U can be motivating in the context of sexual health, and for overall holistic health and well-being.



Using the patient’s own voice can be a powerful tool in disseminating U=U messaging.

Contact Information

For more information, support, or technical assistance, please contact us at hip@pcdc.org.



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Endnotes

- 1 CDC, <https://www.cdc.gov/globalhivtb/who-we-are/features/amplifying-undetectableuntransmittable.html>
- 2 Calabrese SK & Mayer KH. Providers should discuss U=U with all patients living with HIV. Lancet HIV, February 13,2019, DOI [https://doi.org/10.1016/S2352-3018\(19\)30030-X](https://doi.org/10.1016/S2352-3018(19)30030-X)

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