

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)

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

Ivette



Ivette Chavez Gonzalez is a Latina woman who is HIV positive and is in recovery for substance use disorder. She now does work relating to harm reduction as a peer outreach worker, helping the community to see that there is a way out. She conducts mobile outreach and provides clean syringes in the community to help individuals to reduce their risk of HIV transmission. She encourages HIV testing and provides education to people with HIV about the importance of taking HIV medication to stay healthy and to become and remain undetectable.

Ivette is the CEO and founder of the Giving Back Foundation, an outreach and street-based grassroots organization built on the spirit of unconditional, radical love for those facing barriers to overall stability. The Foundation seeks to support the population's basic needs to restore dignity and promote the well-being of the underserved. The vision of the Foundation is to build a community of care and love that assists New Yorkers impacted by drug use and/or homelessness to facilitate health equity, empowerment, and dignity.

Liza



Liza Pereira has worked in the HIV, Harm Reduction and Hepatitis C field for 8 years. She has been a Peer Specialist, Hepatitis C Linkage Specialist, a Sexual Health Community Liaison, and is currently the Community Liaison at Evergreen Health in Buffalo NY, where she is working to help people in the sex worker industry with linkage to care and other services. She is a graduate of Buffalo State College with a BA in Business Administration. Liza is also a New York State Certified Peer in HIV, hepatitis C, and harm reduction. She was part of the first-ever graduation class of the NYS Certified Peer program in 2016. Liza is a person living with HIV for 29 years, was cured of hepatitis C in 2014 and has been in recovery for 25 years. She is also part of two NYS Department of Health sponsored campaigns, HIV Stops with Me and NY Cures Hep C. In her personal life, Liza enjoys spending time with her 5 children, 10 grandchildren, and 2 great-grandchildren.

Video Details

Ivette

Ivette is a community outreach worker. She is a long-term survivor and has been in recovery from substance use since 2015. This is a good video to employ if you are seeking to engage with clients that are active substance users or in recovery. Video length: 5 minutes, 46 seconds. Click [here](#) to view.

Liza

Liza has been in recovery since 1999 and is a long-term survivor. She has a family history of substance use disorder, and her parents eventually died from AIDS. This video can serve as a powerful tool to open conversation with clients who are active substance users as it reflects both the consequences as well as the hope that can come from managing their addiction(s). Video length: 5 minutes, 1 second. 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?
 - 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)

CDC Disclaimer

PCDC’s High Impact Prevention (HIP) provides technical assistance (TA for the Northeast Region of US). PCDC Capacity Building Assistance’s (CBA) program materials and activities are supported by Funding Opportunity Announcement PS19-1904, component 2A (Clinical HIV Testing and Prevention for Persons with HIV) Number 6 NU65PS923669 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of PCDC and do not necessarily represent the official view of the Centers for Disease Control and Prevention.