Undetectable Equals Untransmittable: Building Hope and Ending HIV Stigma

Nothing Without Us: HIV and Social Justice
Iris House 13th Annual Women as the Face of AIDS Summit
May 7, 2018

Together, we can change the course of the HIV epidemic...one woman at a time.

#onewomanatatime
#thewellproject

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About The Well Project

• Non-profit organization with a mission to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls
• Leverages technology to improve health outcomes and increase quality of life for women and girls living with HIV
• Provides accessible and comprehensive #information, #community support, and #advocacy building
• Access our resources and join our community at www.thewellproject.org

www.thewellproject.org
A community of HIV advocates, activists, researchers, and organizations around the world uniting to clarify and disseminate the revolutionary but largely unknown fact that people living with HIV on effective treatment do not sexually transmit HIV.

Launched in early 2016 by a group of people living with HIV who created a Consensus Statement with global experts to clear up mixed messages about the science of U=U.

That Statement was the genesis of the U=U movement that is sharing the U=U message to dismantle HIV stigma, improve the lives of people living with HIV, bolster treatment advocacy efforts, and bring us closer to ending the epidemic.
Speakers

Nancy Duncan, HIV Testing Counselor, Planned Parenthood, CFAR North Shore University Hospital

Lillibeth Gonzalez, HIV/AIDS Community Health Educator, GMHC

Michelle Lopez, Campaign Coordinator for CDC HTW Campaign for New York, Peer Lead Consultant, ACRIA

Krista Martel, executive director, The Well Project

Bruce Richman, Ed.M, JD, founder, executive director, Prevention Access Campaign and Undetectable = Untransmittable (U=U)

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Agenda

• Introductions
• U=U Overview
  – Treatment as prevention
  – Research
  – U=U campaign
  – Why didn’t I know about this?
  – Issues specific to women
• Panel Discussion of U=U
• Q&A

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U=U Overview
What Is “U=U”? 

When a person living with HIV is taking HIV drugs and their viral load has reached **undetectable** levels (not enough HIV in their bloodstream for a test to measure), that person cannot transmit HIV to a partner who is HIV-negative.

HIV community members, advocates, and experts refer to this as "**Undetectable Equals Untransmittable**" ("**U=U**")

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Treatment as Prevention (TasP)

- Foundation of U=U
- Refers to ways we can use HIV treatment regimen to lower the risk of spreading HIV
- For people living with HIV (HIV+):
  - Taking HIV drugs can reduce viral load
  - Blood, vaginal fluids, and/or semen (cum) is much less likely to transmit HIV to others
  - Mixed-status couples (one partner HIV+, one HIV-) who want to have babies are more likely to safely conceive "the old-fashioned way"

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How HIV Treatment Makes U=U

• Chance of passing on any virus has to do with amount of virus (viral load) in body fluids
• HIV drugs prevent virus from reproducing (making copies of itself)
• When an HIV treatment regimen works...
  – HIV is unable to reproduce
  – HIV will not infect new cells in your body
  – Viral load is undetectable, which means...
    • You will have a healthier immune system
    • You cannot transmit HIV

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How HIV Treatment Makes U=U

- HIV drugs cannot cure HIV
  - Even when viral load is undetectable, there are still 'resting' or latent HIV cells in certain areas (reservoirs) of your body (e.g., GI tract (gut), brain, or bone marrow)

- ... but having an undetectable viral load means there is no detectable trace of virus in the blood
  - There may be in the genital tracts (e.g., semen, vaginal secretions)
The "Swiss Consensus Statement" (2008)

- Group of HIV care providers in Switzerland produced a paper aimed at other doctors in their country
- Agreed that an HIV+ person who had had an undetectable viral load for at least 6 months on HIV treatment had a **negligible risk** (so small or unimportant that it is not worth considering) of transmitting HIV
  - Based on new data and their clients’ experiences
The Research Behind U=U

**HPTN 052 (2011 – interim /2015 - final)**

- Large study – more than 1,500 mostly heterosexual, mixed-status couples
- Randomly divided into an early treatment and late treatment group
- *No cases of transmission when the HIV+ partner had an undetectable viral load*

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The Research Behind U=U

• HPTN 052 *changed HIV prevention*
  – Put an additional tool – treatment for people living with HIV – in prevention toolbox

• However, *information not well known or understood* outside of HIV advocate and expert circles
  – Mainstream media accounts of this news was often confusing, misleading, loaded with HIV stigma

• Many *people living with HIV were not aware* of this exciting development

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PARTNER (2016)

- Looked at HIV transmission risk in heterosexual and gay mixed-status couples
  - Partners living with HIV on HIV treatment with undetectable viral loads
- After 58,000 instances of sex, among 900 couples who were not using condoms, zero cases of HIV acquisition
- Results of PARTNER and follow-up results of HPTN 052 published in mid-2016
  - Still confusion, misinformation, silence around topic

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The U=U Campaign

#UequalsU

- Launched by health equity program Prevention Access Campaign (PAC) in early 2016
- A project led by people living with HIV
- Unites global community of HIV advocates, activists, researchers, community partners
- Mission is to clarify and share the fact that people living with HIV who are HIV treatment with an undetectable viral load cannot transmit HIV when they have sex

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Community and Medical Experts Agree

• 2016: U=U campaign released first-ever global consensus statement confirming science behind U=U

• >600 HIV experts, advocacy groups, service organizations, departments of health from 76 countries have endorsed U=U message

• Statement translated into 15 languages (so far)
  – The Well Project proudly endorsed consensus statement in April 2017

• Partners share info in ways that work for their communities

• Part of a strategy to break down HIV stigma; provide hope; improve lives of people living with HIV; advocate for access; move closer to ending HIV as a worldwide epidemic

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Why Didn't I Know About This?

• Shifts in attitudes, beliefs, behaviors take time
  – For decades, condom use held up as only sure way to stop spread of HIV
  – Condom use often encouraged through campaigns and activities based in fear of contact with HIV
  – U=U as an HIV prevention strategy has been a difficult message for many to accept
  – STIs and unwanted pregnancies remain important issues
    • Condoms prevent these; HIV treatment as prevention does not
**Intersectional** forms of stigma affect whether U=U message is delivered

- People living with or vulnerable to HIV are often the same people whose sexuality carries stigma and judgment
  - E.g., transgender people, women of color, older women, young women, people living in poverty
  - Freedom to enjoy their sexual lives is often limited, not celebrated
  - Recognizing U=U helps alleviate stigma and judgment

- Recent study found that almost 40% of HIV+ women in the U.S. (as opposed to close to 90% in the UK) studied had not been told about U=U by providers

- In another study, participants vastly overestimated their own transmission risk
Important U=U Issues for Women

Relationship Power Dynamics

• Part of how HIV epidemic continues to flourish among women globally
  – Women often cannot demand that their partners use condoms due to uneven power dynamics, fear of violence
  – May follow that women are unable to ask about their partners' treatment status or viral load
    • Partners may not honor a woman's request to use condoms or other barriers based on their undetectable viral load

• **More research and insight is needed** into ways U=U may be affected by partner power dynamics for women

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Important U=U Issues for Women

Breastfeeding

• While HIV treatment can decrease HIV transmission through breast milk, there may still be some risk
  – Having undetectable viral load in blood may not guarantee undetectable viral load in breast milk
  – Other factors that affect HIV transmission through breastfeeding
    • E.g., mastitis (breast infection that can occur in breastfeeding mothers) can increase viral load before a woman knows she has it
  – In places without refrigeration or safe water, the risk from formula feeding with unsafe water – and the immune benefits of breastfeeding – may outweigh HIV risk

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Breastfeeding

• In high-resource areas with safe water, breastfeeding isn’t recommended for women living with HIV
  – Experts on HIV and women's health divided as to whether or not this should be the case in U=U era

• Some providers suggest:
  – That women be given all information to make their own choice
  – Be supported to continue taking their HIV treatment
  – Be counseled on reducing potential harms of breastfeeding if they choose to do so

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Important U=U Issues for Women

HIV Criminalization

• As of April 2016, 72 countries and >30 U.S. states had laws making it a crime for a person living with HIV to do things (e.g., consensual sex) that are not crimes for HIV-people

• These laws build HIV stigma and discrimination into the legal system

• Do not take into account the realities of living with HIV in the era of U=U
  – U=U does not yet change status of existing laws

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Important U=U Issues for Women

HIV Criminalization

• In opposing these laws, it is important not to stigmatize or criminalize those that have detectable viral loads

• Women, especially, may have a harder time getting their viral loads to undetectable, for reasons including:
  – Being more likely to be diagnosed later in life than men
  – Prioritizing the health of others over their own
  – Higher rates of violence, poverty, instability that come with these social determinants of health that make it hard to be consistent with medication

• Criminalizing people based on HIV status is never appropriate, regardless of viral load

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The Bottom Line

• Increasing awareness that having an undetectable viral load means that people living with HIV will not transmit the virus can have a **dramatic impact on public and personal perceptions of HIV**

• HIV stigma = biggest barrier to ending HIV epidemic

• Important to break down stigma wherever possible by providing access to information, community support, advocacy -- all of which build **hope**

• U=U has the potential to address all kinds of HIV stigma

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The Bottom Line

- While researchers must continue to examine promise and impact of treatment as prevention, *the science that is currently available strongly supports U=U*
- We need to make sure that *all people living with HIV, or vulnerable to becoming HIV+, have access to this life-altering information*, so that they can make informed decisions about their own sexual health and lives

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Panel Discussion

Nancy Duncan, Lillibeth Gonzalez, and Michelle Lopez
Learn More!

- To learn more about this topic, and for links to articles featuring more details, please read the full fact sheet on this topic:
  - Undetectable Equals Untransmittable: Building Hope and Ending HIV
  - Indetectable es igual a intransmisible: infundir esperanza y eliminar el estigma

- Visit Prevention Access Campaign #UequalsU
  - @preventionAC

- For more fact sheets and to connect to our community of women living with HIV, visit:
  - www.thewellproject.org
  - www.facebook.com/thewellproject
  - www.twitter.com/thewellproject

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Additional Resources

- **U=U: Undetectable = Untransmittable** (Video)
  - from Prevention Access Campaign
- **If I Am Undetectable I Can't Transmit the HIV Virus** (Video Blog)
  - by Maria T. Mejia
- **HIV Undetectable = Untransmittable: Interview With Bruce Richman**
  - by Nelson Vergel, from Program for Wellness Restoration
- **Infant Feeding Basics: For Women Living with HIV in the US** (PDF)
  - from HIVE
- **If We Act to Remove Structural, Behavioral and Social Barriers, We Can End the HIV Epidemic With the Medicines We Already Have: A Conversation With Dr. Ben Young**
  - by Olivia G. Ford, from TheBodyPRO.com
- **Why, for HIV, Undetectable = Untransmittable**
  - by Roger Pebody, from TheBody.com

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Thank You!

The Q & A will come from the questions submitted to the presenters through the chat box during the webinar session.