

How do you say U=U?

Undetectable = *Untransmittable*. You know what that means. But in the United States, most people living with HIV, providers, policy makers and the public still don't.

This radical fact can transform lives and the field when communicated properly.

When describing the "risk" from one human being to another in the most intimate moments of their lives, it's important to be impeccable with words and attitudes. When speaking with people living with HIV, their sexual partners, and the wider community, it is important to describe U=U in a way that inspires confidence and does not promote unnecessary doubts or fear.

Below are a few pointers we've gathered from our partners in the U.S. and around the world.

U=U BELONGS TO EVERYONE

It's yours. We didn't copyright it.

U=U is based on the science of TasP, pioneered in 2007 by Dr. Julio Montaner, who was also one of the earliest signatories to the U=U consensus statement. The phrase "*Undetectable = Untransmittable* (U=U)" was created by the community and researchers to easily convey the TasP science in a more definitive, descriptive and empowering way.

The phrase "U=U" is now being communicated at the highest levels in the field:

- NIH Director Dr. Francis Collins recently wrote a blog supporting U=U¹.
- NIAID Director Dr. Anthony S. Fauci and Director of the Division of AIDS at NIAID Dr. Carl Dieffenbach recently wrote an article in JAMA supporting U=U².
- NIH OAR Director Dr. Maureen Goodenow wrote a blog about why U=U is game changer³.
- CDC Director Dr. Robert Redfield referred to U=U in a recent speech⁴.

The phrase is being used in impressive marketing materials, social marketing campaigns, outdoor campaigns and treatment guidelines, many of which can be found on our website (uequalsu.org), by:

- International institutions including: UNAIDS⁵, International AIDS Society⁶, and ICASO⁷.
- **U.S. public health departments** including: New York State⁸, New York City⁹, Washington D.C¹⁰, Baltimore¹¹, and Minneapolis¹².
- **U.S. nonprofit organizations** including: HIVMA¹³, Long Island Pride for Youth¹⁴, Equitas Health¹⁵, AIDS Project Rhode Island¹⁶, and Housing Works¹⁷.
- Pharmaceutical companies including: ViiV¹⁸, Janssen¹⁹, Merck²⁰, and Gilead²¹.
- **Health ministries** including the UK²², Canada²³, Vietnam²⁴, Australia²⁵, and Monaco²⁶.

U=U has been embraced and translated by grassroots activists and people living with HIV networks from diverse parts of the world including Armenia, Botswana, China, Japan, Kazakhstan, Moldova, The Netherlands, New Zealand, Portugal, Russia, South Africa, South Korea, Uganda and many more.

Over 800 organizations from nearly 100 countries have signed on to the U=U campaign.

So, please feel confident about using U=U. Or use any phrase that gets the message across in accurate and authentic ways.



MAKE U=U A PRIORITY

As you create statements, videos, speeches, newsletters, please keep in mind that millions of *people don't know about or believe U=U*. Every communication is an opportunity to change the life of a person living with HIV. It is the most important information those of us in the field can share.

Make it prominent so it has the best chance of being seen, not buried in paragraph six or near the end of a video where it could go unnoticed.

U=U fits into many areas of the field:

- **HIV stigma** U=U is the greatest opportunity we've had to dismantle it.
- **HIV treatment** U=U is an added incentive to initiative and adhere to treatment and to stay engaged in care.
- **Sexual and reproductive health** U=U means we can have sex and conceive children without fear of transmission or alternative and expensive means of insemination.
- **Mental health –** U=U reduces the fear and shame of transmission which has lifted people with HIV out of depression and social isolation.
- **HIV prevention** U=U is the most effective way to prevent HIV transmission.
- Access to treatment and services U=U is the public health argument for access.
- **HIV criminalization** U=U is an important part of the modernization toolbox.

THE BASICS ARE EASY

The basic rules are not complex. It's about TLC:

- 1. Treatment stay on treatment as prescribed
- 2. Labs get labs done regularly
- 3. Care stay in care

This is easy to understand, but structural inequalities and social determinants of health make it difficult or impossible for far too many to do.

Other items to keep in mind:

- The threshold for U=U is under 200 copies/ml, synonymous with viral suppression.
- Achieving an undetectable viral load can take up to 6 months of ART. Once achieved, continued adherence is required.²⁷
- U=U only prevents HIV. Condoms help prevent other STIs and pregnancy.
- U=U only applies to sexual transmission, not to breastfeeding or needle sharing.
- U=U may not exempt people with HIV from disclosure laws, which are unjust and bad for public health regardless of viral load.

BE CLEAR AND CONSISTENT

Use definitive and easy to understand phrases such as "can't pass it on" "cannot transmit," and "no risk." You can even say "zero risk". Please visit our website²⁸ for many sources to back you up.

Avoid phrases that convey even slight risk or are ambiguously defined like "nearly impossible", "extremely low", "essentially no", and "virtually impossible." Any perceived window of risk, no matter how slight, may be



considered "still a risk" and sourced by those who wish to stigmatize and harm us. If you see such phrases, please speak out!

AVOID OVERLY CAUTIOUS PHRASES

If someone has an undetectable viral load, stays on medication as prescribed and stays in care, they can feel confident in U=U as an HIV prevention method. Overly cautious attitudes undermine the message and can have a profound negative impact.

We call these the "big erasers":

• "I believe U=U, but use a condom and/or PrEP just in case" conveys doubt about U=U.

A condom is not necessary to prevent HIV transmission from someone with an undetectable viral load. Condoms may be helpful to prevent other STIs or unintended pregnancy or if adherence is a challenge for the partner living with HIV.

Similarly, PrEP is not necessary to prevent HIV transmission from someone with an undetectable viral load. Some people may choose to use PrEP if multiple sexual partners are involved or if adherence is a challenge for the partner living with HIV.

Other prevention methods like condoms and PrEP can provide an extra sense of security and shared responsibility.

• "You're only as good as your last viral load" is terrifying. This means a person with HIV could be "infectious" at any moment even if they're adherent and their recent viral load was undetectable. It doesn't happen²⁹. It's important to convey that once undetectable status is achieved and a person with HIV stays on treatment, gets labs done regularly and stays in care, that person and sexual partners can feel confident about having sex without any risk of HIV transmission.

STAY IN THE REAL WORLD - AVOID SCARING WITH STATISTICS!

We strongly advise against bringing up the theoretical world of statistics related to U=U. They are not helpful. But if you feel you must, then explain that a theoretical risk is not real-world risk. There will *always be a theoretical risk because science can't prove zero risk about anything*. For instance, we can't prove that your head won't explode right now, but we don't advise people to wear helmets.

We can't underscore enough that scary statistics are harming people. Case in point:

Sanjay Johnson, a 25-year-old black man is awaiting trial for exposure to HIV despite being undetectable. His motion for dismissal was denied by the judge who considered there may be a risk based on this phrase³⁰ "we cannot rule out the risk may not be zero" from an out of date federal health department fact sheet that has since been updated. He is facing up to 30 years.

SAY ZERO

The world's leading scientists and many leading organizations are saying "zero."

Anthony S. Fauci, M.D., "From a practical standpoint, the risk is zero."³¹



- Dr. Alison Rodger (lead author of PARTNER 1 & 2) at AIDS 2018: "If you're on suppressive ART, you are sexually noninfectious. The risk is zero," and again "It's very, very clear the risk is zero." 33
- Dr. Carl D. Dieffenbach: "For somebody who is in a discordant couple, if the person [with HIV] is virologically suppressed, 'durably' --means there is no virus in your system, hasn't been for several months -- your chance of acquiring HIV from that person is ZERO, let's be clear about that: ZERO."

The British HIV Association is encouraging members to say ZERO:

"We recommend consistent and unambiguous terminology when discussing U=U such as "no risk" or "zero risk" of sexual transmission of HIV, avoiding terms like "negligible risk" and "minimal risk." 35

UNAIDS

"A person with an undetectable viral load has no chance of passing on HIV." 36

PROMOTE ON SOCIAL MEDIA

Communicate consistently, especially on social media. It takes repetition to unlearn over thirty-five years of fear of HIV and people with HIV. For example, follow Matthew Hodson, CEO of NAM aidsmap³⁷ (UK), to see how it's done brilliantly on Twitter. If you include #UequalsU, more people are likely to see and share it. Sample tweets are at the bottom of this document.

LEAVE NO ONE BEHIND

We must be conscious in communications to avoid equating viral load with value. Half of the people living with HIV in the U.S. do not have undetectable viral loads often by circumstances out of their control. We must use U=U as a public health argument for universal access to treatment and services not only in the US but in other parts of the world with limited or no access to treatment or diagnostics so all people with HIV have the opportunity to stay healthy and benefit from U=U.

IT'S TIME

All of us have an exciting opportunity to help transform lives and the field by sharing this radical fact. HIV stigma is a public health crisis, and U=U is an effective response. There's no time to waste!

Thank you for being an integral part of the global revolution in what it means to live with HIV.

Prevention Access Campaign #UequalsU

RESOURCES

There are many excellent U=U Resources³⁸ being developed in the US and around the world. We will continue to share as they become available. Below are some resources (also available on uequalsu.org) we think may be useful:

Customizable & downloadable U=U posters, videos, gifs (Prevention Access Campaign / ViiV Healthcare) ³⁹ New York State Untransmittable Campaign (New York State) ⁴⁰ DC Takes on HIV Campaign (Washington, DC) ⁴¹ Minneapolis Dept of Health (Minneapolis, MN) ⁴²



U Equals U Maryland (Baltimore)⁴³

Downloadable U=U posters (Saving Lives- UK)44

U=U Fact sheet (NIAID)⁴⁵

U=U for Providers (HIVMA)⁴⁶

U=U Fact Sheet (NYC DOHMH)⁴⁷

U=U Fact Sheet (i-base UK- updated with PARTNER 2 study)⁴⁸

Why is U a Game Changer? (NIH OAR - Letter from Dr. Maureen Goodenow)⁴⁹

U=U Toolkit (Ontario AIDS Network - Canada)50

The liberating message of 'Undetectable = Untransmittable' (Members of Women's Research Institute, a program of The Well Project)⁵¹

U=U in the context of women's health (Women's Research Institute, a program of The Well Project)⁵² U=U and semen (NIAID)⁵³

The Undetectables website (Housing Works)⁵⁴

Interactive U=U Chat website – (Undetectable love / PleasePrepMe.org)⁵⁵

Courtney Act U=U video (New Zealand AIDS Foundation)⁵⁶

Uber Date "Drop Your Load" video (New Zealand AIDS Foundation)⁵⁷

PWN U=U video (PWN USA)58

SFAF U=U video (San Francisco AIDS Foundation from our website)⁵⁹

Daddy Hunt Video (Daddy Hunt)60

In Bed with U=U video (TIM - Australia)61

Sample Tweets

- 1. [ORG NAME] stands with science. People living with HIV on effective treatment cannot pass on HIV through sex. #UequalsU #ScienceNotStigma Learn more at: www.uequalsu.org
- 2. HIV stigma is a public health emergency & #UequalsU is an effective response. It's time to take action and share the great news! #ScienceNotStigma Learn more at: www.uequalsu.org
- 3. #UequalsU is a public health argument for universal access to treatment & care to save lives and prevent new transmissions. Awareness about U=U is essential for ending the epidemic. #LeaveNoOneBehind
- 4. Communicating #UequalsU saves lives and fights stigma. Download customizable posters, videos, and gifs to educate about U=U and encourage engagement in care at www.positiveseries.org.
- 5. A person living w/HIV who is on treatment & has an undetectable viral load has zero chance of passing HIV through sex. Millions of people w/HIV still haven't been informed by their providers about the life changing science. There's no time to waste! Share the news! #UequalsU

Endnotes:

¹ https://directorsblog.nih.gov/2019/01/22/for-hiv-treatment-is-prevention/

² http://bit.ly/UUJama19

³ https://mailchi.mp/od.nih.gov/letter-from-the-oar-director?e=9841b11756

⁴ https://www.youtube.com/watch?v=j4OK78T5J0Q&feature=youtu.be

⁵ http://www.unaids.org/en/resources/presscentre/featurestories/2018/july/undetectable-untransmittable

⁶ https://drive.google.com/drive/folders/1sHb7iOGGAQa5VG4yFJ1sAmomY72L-G--?usp=sharing

⁷ http://icaso.org/wp-content/uploads/2018/09/Understanding-UU-for-Women.pdf

⁸ www.untransmittable.org

⁹ https://www1.nyc.gov/site/doh/health/health-topics/aids-hiv.page

¹⁰ http://dctakesonhiv.com/

¹¹ www.uegualsumaryland.org



- 12 http://www.health.state.mn.us/divs/idepc/diseases/hiv/uu/index.html
- ¹³ https://docs.wixstatic.com/ugd/de0404 586fdd336e1c4efeb0b173960338d8f7.pdf
- ¹⁴ https://longislandcrisiscenter.org/prideforyouth/undetectableuntransmittable/
- 15 http://equitashealth.com/blog/equitas-health-to-launch-statewide-hiv-awareness-campaign-on-december-1/
- ¹⁶ http://aidsprojectri.org/faqs/#u-u
- 17 http://www.liveundetectable.org/
- ¹⁸ www.positiveseries.org, https://www.viivhealthcare.com/en-gb/our-stories/partnerships-key-populations/u-u-undetectable-equals-untransmittable/
- ¹⁹ https://www.preventionaccess.org/scholars
- ²⁰ <u>https://www.mrknewsroom.com/news/company-statements/merck-endorses-prevention-access-campaign-undetectableuntransmittable-consen</u>
- ²¹ https://www.preventionaccess.org/news-opt/gilead-science-inc-joins-the-uu-campaign
- 22 https://www.nhs.uk/conditions/hiv-and-aids/prevention/
- ²³ https://www.newswire.ca/news-releases/canadas-minister-of-health-calls-for-end-to-stigma-on-world-aids-day-701707031.html
- ²⁴ https://vietnamnews.vn/society/481025/toolkit-released-to-combat-hiv-related-stigma-and-discrimination.html
- ²⁵ http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-bbvs-1/\$File/HIV-Eight-Nat-Strategy-2018-22.pdf
- ²⁶ http://www.fightaidsmonaco.com/
- ²⁷ https://jamanetwork.com/journals/jama/fullarticle/2720997?alert=article
- ²⁸ Www.preventionaccess.org
- ²⁹ http://i-base.info/u-equals-u-qa/
- 30 http://www.thebody.com/content/81289/sanjay-johnson-faces-prison-sentence-in-arkansas-h.html
- 31 http://www.imstilljosh.com/fauci-the-risk-is-zero/
- 32 https://www.medscape.com/viewarticle/899892?src=wnl edit tpal&uac=248764HY&impID=1696856&faf=1
- 33 https://www.youtube.com/watch?v=90rwMm18Ry4&t=4s&list=PLMuV5dq7YMFuaMfvhexWqHiFKJ9iiMu n&index=12
- 34 https://www.youtube.com/watch?v=MGSTO2CSFrU&feature=youtu.be
- 35 http://www.eatg.org/news/bhiva-encourages-universal-promotion-of-undetectableuntransmittable-uu/
- 36 http://www.unaids.org/sites/default/files/media asset/undetectable-untransmittable en.pdf
- ³⁷ https://twitter.com/Matthew Hodson
- 38 http://www.preventionaccess.org/resources
- 39 http://www.positiveseries.org/
- 40 www.untransmittable.org
- 41 http://dctakesonhiv.com/
- 42 http://www.health.state.mn.us/divs/idepc/diseases/hiv/uu/index.html
- ⁴³ www.uequalsumaryland.org
- 44 http://www.savinglivesuk.com/undetectable-untransmittable/
- 45 https://www.niaid.nih.gov/news-events/10-things-know-about-hiv-suppression
- 46 https://docs.wixstatic.com/ugd/de0404 586fdd336e1c4efeb0b173960338d8f7.pdf
- 47 https://docs.wixstatic.com/ugd/de0404 9953eed1181949618d205be7e368635f.pdf
- 48 https://docs.wixstatic.com/ugd/de0404 7a7cc26c70b64dddbe91224192f01911.pdf
- 49 https://mailchi.mp/od.nih.gov/letter-from-the-oar-director?e=9841b11756
- 50 https://oan.red/wp-content/uploads/2018/11/OAN-Toolkit-Final.pdf
- ⁵¹ https://www.healio.com/infectious-disease/hiv-aids/news/print/infectious-disease-news/%7B41e2b2a5-fa72-4bb1-be1d-
- a76e544ded93%7D/the-liberating-message-of-undetectable--untransmittable
- 52 https://www.thewellproject.org/sites/default/files/2018 WRI Issue Brief Final.pdf
- 53 https://www.niaid.nih.gov/diseases-conditions/hiv-treatment-viral-reservoir-hiv-dna
- ⁵⁴ https://liveundetectable.org/
- 55 http://undetectable.love/
- 56 https://www.youtube.com/watch?v=N8BaUaEoD6A
- 57 https://www.youtube.com/watch?v=LilzTRndNvI
- 58 https://www.youtube.com/watch?v=pYOjRg8l7jo
- 59 https://youtu.be/AQXFt9j5mGo
- 60 https://www.youtube.com/watch?v=-Av34 SgsNA
- 61 https://www.youtube.com/watch?v=vMK1SRjZ8iw