Ending the Epidemic Task Force Recommendation Form



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Q1: OPTIONAL: This recommendation was submitted by (please provide your first and last name, affiliation, and email address)

First Name Jeton

Last Name Ademaj

Affiliation ACT UP New York
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Q2: Title of your recommendation "Provable Undetectability: Incentivizing Treatment

Adherence and Defanging Stigma by making viral

suppression confirmable to 3rd parties"

Q3: Please provide a description of your proposed recommendation

my own primary motivation in achieving "consistently undetectable viral load" through elite medication adherence was in gaining the ability to forthrightly declare that achievement to strangers, so that they would be less likely to categorically reject me.

Treatment as Prevention remains a theoretical construct to those at risk of HIV infection. there is presently no way to know who is telling the truth in regards to their own claimed viral suppression. Thus, they simply choose to serosort based on verbal claims, and in areas of both high HIV prevalence and high HIV stigma, that will often increase their own risk and embarrass and alienate them from testing. further still, that internalized stigma makes treatment uptake and treatment adherence each less likely, and less successful when attempted.

the idea is simply a piecemeal form of "secure portable digital healthcare records", but it is one with much of the necessary underlying infrastructure already in place. creating opt-in, voluntary mirrors of official state health records would allow individuals to either privately or publicly advertise secure versions of their testing records. my interviews with almost 200 men who have sex with men has indicated that such a system is desirable if it can be trusted, and the only entity at all that is regarded as both competent and fearsome enough to discourage fraud is State and Federal government.

objections voiced to this idea have been based on feared abuse of government power, and feared "erosion of the condom culture".

however, the remaining menu of incentives for treatment adherence is quite sparse: comic books about "undetectability", social media campaigns declaring "stigma bad", and nominal cash payments to HIV+ people to bribe them into adherence present more limited potential for encouraging success and defusing stigma.

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Q4: For which goal outlined in the Governor's plan to end the epidemic in New York State does this recommendation apply? (Select all that apply)

Linking and retaining persons diagnosed with HIV to health care and getting them on anti-HIV therapy to maximize HIV virus suppression so they remain healthy and prevent further transmission

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Other (please specify) the bulk of the HIV prevention paradigm marketed to people at risk for 30 years is based on systematic distrust of HIV positive individuals. attempts to frame or direct that mistrust only to those who are not aware of their own HIV infection have failed to limit the reflex of the wider society to subconsciously distrust all HIV+ people. stigma and criminalization quickly followed, and continue to intensify, destigmatizing HIV in a self-propagating manner, using the inherent mechanics of courtship and sexual attraction to propel forward a wider appreciation of biomedical risk reduction, is an entirely unexplored way to triangulate between stigma, prevention and treatment.

Q5: This recommendation should be considered by the following Ending the Epidemic Task Force Committee (Select all that apply)

Prevention Committee: Develop recommendations for ensuring the effective implementation of biomedical advances in the prevention of HIV, (such as the use of Truvada as pre-exposure prophylaxis (PrEP)); for ensuring access for those most in need to keep them negative; and for expansion of syringe exchange, expanded partner services, and streamlined HIV testing by further implementing the universal offer of HIV testing in primary care, among others. The Committee will focus on continuing innovative and comprehensive prevention and harm reduction services targeted at key high risk populations, as well as grantfunded services that engage in both secondary and primary prevention.

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Care Committee: Develop recommendations to support access to care and treatment in order to maximize the rate of HIV viral suppression. The Committee will promote linkages and retention in care to achieve viral suppression and promote the highest quality of life while significantly decreasing the risks of HIV transmission. Recommendations will also ensure a person centered approach is taken and that access to culturally and linguistically appropriate prevention and health care services is available.

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Housing and Supportive Services Committee:
Develop recommendations that strengthen
proven interventions enabling optimal
engagement and linkage and retention in care for
those most in need. This Committee will
recommend interventions that effectively address
complex and intersecting health and social
conditions and reduce health disparities,
particularly among New York's low-income and
most vulnerable and marginalized residents.
These interventions will diminish barriers to care
and enhance access to care and treatment
leaving no subpopulation behind.

Q6: Does this recommendation require a change to an existing policy or program, or the creation of a new policy or program?

New program,

Other (please specify)

legal consultation is needed to determine if the current names-based reporting legislation requires a tweak to allow the creation of voluntary, opt-in mirrors of current NYS DOH records pairing names and viral load counts. technical consultation is needed to determine infrastructure and implementation requirements.

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| Q7: Would implementation of this recommendation be permitted under current laws or would a statutory change be required? | Unknown |
|---|----------------------------------|
| Q8: Is this recommendation something that could feasibly be implemented in the short-term (within the next year) or long-term (within the next three to six years)? | Within the next year |
| Q9: What are the perceived benefits of implementing this recommendation? | |
| trust, adherence, reduced infectiousness. | |
| Q10: Are there any concerns with implementing this recommendation that should be considered? | Respondent skipped this question |
| Q11: What is the estimated cost of implementing this recommendation and how was this estimate calculated? | Respondent skipped this question |
| Q12: What is the estimated return on investment (ROI) for this recommendation and how was the ROI calculated? | Respondent skipped this question |
| Q13: Who are the key individuals/stakeholders who would benefit from this recommendation? | |
| all infected and all at risk of same. | |
| Q14: Are there suggested measures to accompany this recommendation that would assist in monitoring its impact? | |
| please contact me. | |
| Q15: This recommendation was submitted by one of the following | Advocate |