# Frequently Asked Questions (FAQ) - Index Testing

January 2020

Index testing, a PEPFAR initiative that tracks the contacts of people who test positive for HIV, has potential benefits when done ethically. But index testing is presently being aggressively implemented in ways that cause harm, increase risk of violence and undermine people's rights to consent, confidentiality and safety. Changes must be made to protect individuals and foster community trust in their healthcare system.

For activists and advocates attending PEPFAR in-country retreats, this FAQ provides background and advocacy priorities.

## What is index testing?

Index testing—also called assisted partner notification services (APNS)—asks people who test positive for HIV to voluntarily provide the names and contact information for their sexual and needle-sharing partners and biological children, and then traces those individuals to recruit them for testing.

# Why are there concerns about index testing—and where have they been raised?

Starting in 2018, the Office of the Global AIDS Coordinator (OGAC), started pushing countries to adopt index testing as a core testing strategy. In 2019, PEPFAR started requiring country programs to identify at least 30 percent of new cases through index testing. Meeting this target was a challenge in many contexts. These targets, known as index testing proportion targets, do not reflect the risks associated with index testing, and were set without guidance on detecting and mitigating harm, and without the establishment of a consistent PEPFAR-wide system for monitoring if sites have implemented required safety measures, including screening for intimate partner violence (IPV), altering services accordingly and linking to services when relevant.

These targets put pressure on sites, counselors and other staff to make sure that every person testing positive provide names and contact information. The implementing partners can have their funding threatened if they do not achieve these targets. Combined with a lack of guidance on avoiding harm and an absence of monitoring on compliance with human rights safeguards (particularly for voluntarism and confidentiality), some sites coerced people into sharing contacts leading to violence, and denied medical services to people who declined.

Civil society documented these concerns and other major issues at country and clinic level in a <u>brief released in 2019</u>, in feedback to the COP guidance (December 2018), and documented subsequent harms in a letter signed by 75+ organizations sent to OGAC (January 2020). Specific harms that civil society organizations have documented include:

- Several reports of pregnant women being denied antenatal or PMTCT services unless they
  identify their contacts. In at least one case, the woman refused and the child was born HIV
  positive and later died.
- Reports of violence against sex workers and men who have sex with men who reported their contacts.
- Several reports of facilities providing monetary incentives—such as providing travel reimbursement—only for women who report their contacts.

- Reports of facilities imposing user fees on women who don't bring their partners in for HIV testing.
- Reports of facilities being unable to maintain confidentiality when recruiting contacts for HIV testing and leading to violence against the index client.

### How did OGAC respond to the sign-on letter?

Initial text in the COP 2020 guidance stated that index testing should be halted for all key populations and—separately—no facilities may implement index testing unless and until facilities are assessed as capable of implementing the program safely. However, the Guidance provided no criteria on how facilities can be certified as safe. Importantly, implementing partners do **NOT** know how to assess such criteria or they would have been implemented already. Without specific and clear formal criteria, this instruction will lead to chaotic, dangerous and differing certification standards being implemented.

In subsequent communications from OGAC to the field, this guidance evolved and was narrowly interpreted to apply solely to key population clinics and programs.

USAID, CDC and OGAC have all indicated that they want to involve civil society in certification processes, but core commitments to immediately mitigate harm have not been met.

Countries are continuing to develop plans with targets for percent of individuals diagnosed via index testing.

In sum—the response has been confusing and inconsistent with urgent action and leadership required.

### What can and should civil society be doing now?

#### Ensure the new directives are followed.

Currently, no index testing should be happening at any sites. But those sites should still be active with other testing, prevention and treatment programs. Staff including nurses, counselors and lay cadres involved in HIV testing should be assessing their ability to deliver testing including index testing that is confidential, voluntary, free of stigma and risk of violence. Civil society groups engaged in community-led monitoring can measure and assess this.

At national level ask PEPFAR country team members and government representatives:

- How have you communicated the new guidance from OGAC suspending index testing and targets as part of COP20 planning cycle?
- What tools are implementing partners using right now to certify facility compliance, and to monitor for adverse events? Those tools should be documented and distributed to civil society.
- What is the process for developing a national plan for site certification, remediation, monitoring, assessment and accountability mechanisms for health care workers and implementing partners found not to be following guidelines?
- What funding has been or will be allocated to civil society to monitor and assess the use of index testing?

#### At the facility level, ask:

Are you asking people who test positive for their contacts?

- What steps are you taking to make sure that your testing program is confidential, voluntary, free of stigma and risk of violence, including:
  - How are you assessing community perceptions and experiences of your index testing program? How are you using those assessments to improve your services? Are you having community dialogues, providing anonymous comments box and adding standard questions to client visits?
  - Do you ask people about their fears or the potential for violence if a contact is notified? If yes, do you continue with the notification? How?
  - How is civil society involved in planned assessments and remediation activities, if any are needed?
  - What types of staff training are planned?
  - What services for violence prevention and for survivors of gender-based violence (GBV) or intimate partner violence (IPV) are you connecting with as an element of your testing program?
  - What on-site capacity are you adding to address GBV and IPV?
  - How do you respond when a client says that they don't want to give their contacts?

# Demand that the COP20 planning cycle include innovative, comprehensive testing strategies that link HIV-positive and -negative people to treatment and prevention.

The suspension of the index testing proportion targets is an opportunity to energize a critical discussion about national HIV testing strategies. Planning should include:

- Concrete steps for each program to determine if index testing can be conducted safely and ethically. If so, where and how will those programs be independently monitored. Reference to evidence from the universal test and treat trials (UTT)— these showed community-wide testing approaches that offer services to everyone, regardless of status, help drive down HIV incidence.
- Meeting the needs of adolescents and young people with youth-friendly services that integrate HIV testing with contraception and sexual and reproductive health services.
- "Men's corners," extended hours and mobile testing—these are among the strategies that help reach men.
- Peer-led HIV testing and counseling services for key populations, beyond traditional facilitybased and provider-initiated testing services.

#### Want to learn more?

- New HIV Testing Strategies in PEPFAR COP19: Rollout and Human Rights Concerns—AVAC, amfAR, CHANGE
- Consolidated Guidelines on HIV Testing Services For A Changing Epidemic—WHO
- Open letter-75+ organizations
- PEPFAR COP 2020 Guidance—PEPFAR
- <u>"Partner Notification: A Community Viewpoint." July 2019</u>—Journal of the International AIDS Society.