

# Scaling up HIV testing

## Different perspectives

**This report is based on the workshop  
*PLHIV leadership to scale up testing*  
11th National Congress on STI\*HIV\*AIDS**

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The Global Network of People living with HIV/AIDS (GNP+)  
International Civil Society Support (ICSS)



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# Foreword

This report is based on the workshop PLHIV-leadership to scale up testing which was held during the Dutch national STI/AIDS conference which is held annually on or just prior to World AIDS Day.

The workshop tried to deepen the understanding of testing models and show the diversity of testing models that have been tried with varying degrees of success in different cultures, nations and under different circumstances and specific target groups.

The workshop was based on a role-play showing the arguments fore and against Provider Initiated Opt out Testing as promoted by the WHO/UNAIDS Guidance on HIV testing of May 2007. The role play started a discussion in which participants shared their experiences with HIV testing and the different models of testing.

The workshop was chaired by Dr. Kevin Moody, International Coordinator and CEO of GNP+ ([www.gnpplus.net](http://www.gnpplus.net)). The role-play was acted out by Raoul Fransen – dos Santos, Programme Manager at International Civil Society Support ([www.icssupport.org](http://www.icssupport.org)), and Joost van der Meer, Executive Director of the AIDS Foundation East-West ([www.afew.org](http://www.afew.org)). The report was written by Ejay de Wit. The workshop attracted 26 participants from varying governmental and non governmental organizations inside the Netherlands as well as in the global south.

*Disclaimer: The in role-play expressed opinions do not necessarily reflect those of the persons playing the improvisation, neither of the organization they represent. The role-play was solely meant to initiate the discussion.*

# Introduction

WHO and UNAIDS released a guidance in May 2007, called 'Provider-Initiated Testing and Counseling'. In Provider-Initiated Testing and Counseling, PITC, a doctor will offer a patient an HIV test upon each visit.

According to this guidance, in generalized epidemics testing should be offered to everyone upon each visit to a doctor. In non-generalized epidemics it should be offered to people who either are in high-risk groups, or have clinical manifestations.

The guidance also states that where there is much stigmatization, health authorities should not test every single patient every single time, since that will put the quality of life of that person at risk.

Many questions were raised during the workshop such as whether testing really is the magic bullet to stop the epidemic?

Also: Is it opportune for doctors to initiate HIV testing in Africa and other places in the world where treatment is not available? What happens when you get tested, find out you have HIV, and also find out that you can not access treatment? How will you go back home to your wife or husband, and your children?

And what happens when your tests show negative? Will provider initiated testing initiate the same behavior change as other testing models?

# Pros and cons

To illustrate both sides of the discussion, there was a role-play where a 'good' doctor advocated for routine testing and PITC as he wants to offer the best possible care to his patients; and a 'bad' patient speaking in favor of not offering a routine test upon every visit to a doctor as he wants the freedom to decide when to get tested and how this will affect his life.

## Pro

From the medical point of view, PITC is a good option, certainly with people in higher risk-groups.

To combat the epidemic people must know their HIV status. Scaling-up testing will result in more people knowing their status and those with a positive test result can get treated and take precautions to not spread the virus.

By introducing the opt-out procedure for pregnant women in the Netherlands, the percentage of testing has gotten close to 95 per cent. Knowing your status should be part of good parenthood, because you want your child to be healthy. If the mother is positive, there are effective prevention methods to make sure that the child will be born HIV-negative.

If diagnosed in an early stage of the infection, people can start treatment at a higher CD4 count rate. They have better chances for survival and a higher quality of life than people who start treatment when they get symptomatic.

Screening people for HIV should be as common as screening people for cancer. Why deny someone the right to know his status and improve his health by getting treatment?

## Con

From the PLHIV point of view, PITC can not be a universal model. Testing has a severe impact on both mental health and social life, which is not understood enough. There remain severe shortcomings in both pre and post test counseling.

Knowing your HIV status does not necessarily mean an improvement in quality of life. Many people with low CD4 counts have great quality of life. Even when starting at a lower CD4 count, treatment can still be successful.

People who know their HIV status early in the infection can get problems in their careers, in getting mortgages, making new friends and having sex. More research needs to be done on these impacts before routine testing is introduced globally.

In order to reduce stigma and discrimination, the reasons behind them must be known and dealt with, before labeling everyone with his or her status.

Testing needs to be part of a comprehensive package and directly linked to prevention and care. It is everyone's own human right to know their HIV status, to decide on when and where they choose.

## Discussion

In the discussion participants shared questions, experiences and concerns about PITC. Questions arose like: *“What is the psychological impact of testing in different cultures in case of a positive or a negative result?”* and *“Do people change their life-style after a negative or positive test, to make sure they either stay HIV-negative or keep the virus to themselves”*.

Research done on people with positive test results shows a positive change in their behavior; on people with negative results no such data is available. The psychological impact of testing strikes mainly women. Especially in developing countries women are more likely to visit a health clinic and know their test results. Of those women 30 to 40 per cent have violent or negative outcomes when bringing a positive test home.\* The psycho-social impact and the physical impact for people who bring home a positive test needs to be discussed.

Bad experiences around testing are not rare – and are not restricted to the developing world. During the workshop people quoted own experiences as being sent home with the test results in a closed envelope and about a doctor who informed the parents of a young man, although the man emphasized he did not want his parents to know. Both events happened in the Netherlands. From South Africa came the experience of testing in order to apply for a mortgage. Instead of receiving the test results personally, the bank would simply approve or deny the loan.

With regards to counseling bad experiences were quoted as well. One participant spoke about his Dutch HIV counselor stating that HIV-positive people should not pursue relationships with HIV-negative people. Most doctors in South Africa do not offer counseling at all.

Stigma and discrimination are other serious problems around testing. There is too little known about the reasons behind stigma and how to fight them. When there is much stigma, knowing a positive status will not improve quality of life. Stigma is one of the largest disincentives to get tested. There needs to be improved understanding what stigma means, what people need to be able to deal with it and what can be done to reduce stigma.

While the WHO/UNAIDS guidance presented PITC with a number of cautions, participants at the workshop had no belief these cautions would be heeded by health authorities. Especially in authoritarian states, in Eastern Europe and Central Asia, it is expected PITC will be welcomed as an opportunity to separate “healthy” from “sick” people.

With all these disadvantages, what in contrast should be an incentive for people to get tested?

*“It is important for people to know their status, but testing alone is not enough”,* said a participant from South Africa. *“Besides the need to reduce stigma, there*

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\* USAID/Synergy. Women’s Experiences with HIV Serodisclosure in Africa: Implications for VCT and PMTCT. Meeting Report. Washington, DC: USAID: Mar 2004 (<http://www.synergyaids.com/documents/VCTDisclosureReport.pdf>)

*should also be treatment available and prevention, so that people know how to protect themselves and others."*

Starting treatment should be the main reason to get tested. When treatment is available, testing should be scaled-up and people would be given the choice whether to start treatment or not. However, in many countries treatment is not available, not accessible or not affordable and people often are not treatment literate.

Testing as a prevention strategy causes several concerns. People with negative tests may feel safe to have unprotected sex with each other. They may however be in the early stages of the infection where a recent infection does not show in test results, but people are highly infectious. Even when testing on a very frequent basis, PITC can never be regarded as a safe prevention strategy and brings ethical questions from both a public health and an individual point of view.

WHO has stated earlier that it would be unethical to not screen for other STIs, so doctors should also screen for HIV. With regards to stigma the reasoning is that if everyone knows their status, there will be such an increase of positive people that they will all be accepted by the community and there will be no more stigma and discrimination. Is this sound reasoning? Is there a difference between syphilis and HIV in terms of screening? The consequences of the tests vary. Syphilis can be treated and no one has to know, while HIV has severe consequences in many aspects of people's lives.

Globally, around 85 per cent of all people living with HIV do not know their status. How can we increase testing rates? What models are available, besides the known models of PITC, VCT and self testing? During the discussion people spoke of their experience with three other models of testing:

- **Peer initiated testing**, where peers encourage each other. This model reaches people and provides them with support.
- **Leadership testing**, where HIV-positive leaders encourage the community by getting tested themselves and being present at testing and when getting the results. They are open of their positive status and provide counseling where a test result comes back positive. HIV-positive leaders can learn HIV-negative leaders to understand HIV/AIDS and approach it unprejudiced.
- **Buddy system**, using confidants as a tool. The system is used at a University in Namibia, where students are more likely to share their test result with a single student than to a group. The two can build a relationship in which they can support each other.

Although the perfect model does not exist, participants prefer the ones that are initiated by and supported from the community, provided that they have the building blocks within the community to support people with either a positive or a negative test. Skilled professionals should be available for both pre- and post-test counselling.

# Conclusions and recommendations

- The triad of testing, prevention, and treatment and care all works together. It is one package and these items should no longer be treated as separate focus areas.
- When treatment is available testing should be scaled-up and people should be encouraged to get tested. People should be allowed to make an informed choice whether to start treatment or not. Where treatment is unavailable, testing would be unethical.
- The UNAIDS/WHO Guidance does not manage to quell the alarm bells around PITC.
- All the different testing models have advantages and disadvantages. Models that are initiated by and supported from the community are however preferred, if they have the building blocks to help supporting people, regardless their test results. The community should use the kind of testing that makes sense for itself.
- In political context, where there is no tradition of patients' rights, it is difficult to promote PITC.
- Stigma is one of the largest disincentives to get tested. There needs to be increased understanding what stigma means, what people need to be able to deal with it and what can be done to reduce stigma.