

HATiP

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Main article: Making the world safe for more routine HIV testing

In order to provide universal access to HIV care and treatment by 2010 (if anyone is actually taking that goal seriously), huge numbers of people will have to be tested for HIV throughout the developing world. At present, WHO estimates that fewer than 20% of people living with HIV in low- and middle-income countries know that they are HIV-infected.

But despite an increase in the availability of voluntary counselling and testing (VCT), and despite the increase in uptake of those services whenever antiretroviral treatment is also made freely available, many experts believe that VCT can never meet the need for testing on its own and that different testing approaches are needed.

Several alternative approaches have been proposed:

The first is provider-initiated testing and counselling (PITC). Since health facilities are the most likely (and crucial) point of contact for someone who might be HIV-infected, many healthcare providers have lobbied for policy reform that allows them to provide HIV testing as a routine part of medical care.

Clinicians who have argued in favour of PITC stress the importance of performing the test *for diagnostic purposes*. Knowing a patient's HIV status can be critical information both for the diagnosis and for the management of a number of potentially life-threatening conditions that he or she may present with. For example, knowing the patient's HIV-status is crucial in the pathway towards diagnosis and treatment of smear-negative tuberculosis, and can be important in the differential diagnosis for a number of infections that may be associated with immune deficiency caused by HIV.

However, some are recommending PITC for all patients who come in to use health facilities — even those without any symptoms of HIV-related conditions. PITC of this type is *for HIV screening purposes* — to increase testing among the population.

This is generally called routine opt-out testing, in which the patient is told that the HIV test is routinely recommended, but given relatively little if any pre-test HIV counselling. In theory, the patient has the right to refuse the test if he or she wishes and the post-test counselling is tailored to the result.

Botswana's routine opt-out testing programme is the flagship for this approach but it has both been highly praised and much maligned. Although the programme has led to over 40% of the population being tested (and a great increase in the number of people on treatment), some patients have complained of coercion or lack of consent for testing.

A final approach is universal screening that attempts to test the population comprehensively. Supporters of universal screening believe that even routine testing won't reach people who avoid health services (for example, in many parts of Africa, men won't go to a clinic unless they are practically on their death beds).

Universal screening could theoretically be mandatory, routine, or it may involve door-to-door (or community by community VCT — with substantial pre-test counselling).

However, even when a universal testing programme involves informed consent, it is debatable whether such comprehensive testing would be truly voluntary for everyone in the household (when for example, the husband makes the decision for his wife or the tribal leader decides that his community be tested). One such universal testing campaign is supposed to be underway to screen Lesotho's population of 1.8 million.

We wrote about some of the pros and cons of these approaches in a HATIP several months ago (see

<http://www.aidsmap.com/cms1174742.asp>).

Since that time, there have been several interesting developments.

A call for mandatory confidential testing in South Africa

In October, Dr. Francois Venter, head of the South African HIV Clinicians Society made international headlines by calling for universal HIV testing in his country — arguing that everyone has a responsibility to know their own status. He said that even routine opt-out programmes wouldn't identify many HIV-infected people until it was too late. He suggested that perhaps people should have to provide evidence that they had been tested (not their actual test results), whenever they dealt in any way with bureaucracy (such as when they get their driver's license).

Shooting somewhat from the hip, Dr. Venter suggested that, in a generalised epidemic where literally millions of people don't know their status, mandatory testing might not be such a bad thing if it were provided in an atmosphere where confidentiality is maintained, and good counselling and support services are in place — it might certainly be better than the current system where hundreds of thousands are dying because they rarely get tested and access services.

However, it didn't go down well in all quarters. For example, Mark Heywood, of the Treatment Action Campaign, was quoted in the press as disapproving of Dr. Venter's stance, "the suggestion that we should introduce some sort of coercive thing, that's pushing it ridiculously."

But Dr. Venter says that he simply wants to move the debate forward to stimulate a discussion about alternative ways to get people into care and services — trying to get people to 'think outside the box' of VCT.

"Some people are doing some pretty innovative stuff now," said Dr. Venter. He referred to a consultation on VCT in Pretoria for PEPFAR in March 2007 that he recently attended "to present my extremist views." Yet, he said that "a lot of people there echoed what I was saying, which is it that the endpoint is not the HIV test - it's entry to care and that's where we are actually crap because we do not have good care systems for taking people — who are healthy and do not need ARV's — on and for retaining them in care."

"A lot of the old fashioned VCT people behave as if this is a virus that's going to sit around and do nothing until you're ready to take it on. But for me, it's like pregnancy: I can diagnose you soon after you're pregnant or I can diagnose you when your tummy is out to here. And that's what's happening with HIV, you don't have time to sit around and wait forever. People do need time to assimilate the information. Waiting and waiting till somebody is willing to come forward and to give their consent to have the test actually means that very few South Africans will ever come forward for a test. It is maybe not the best model. It hasn't worked or it's not being done properly. But the point is, I think that we need a new model."

Universally slow testing in Lesotho

However, there can also be problems putting new models in practice. Also in October 2006, an excellent article from IRIN Plus News in the end of October reported that the Lesotho's universal testing programme, the Know Your Status Campaign was having considerable difficulty actually getting off the ground (see

http://www.plusnews.org/AIDSreport.asp?ReportID=6476&SelectRegion=Southern_Africa). Ten months after the programme was slated to begin, testing volunteers complained about a lack of support (travel and food stipends) and rapid testing kits. Meanwhile, the programme coordinators complained about having too few counsellors (they had only mobilised about a quarter of the volunteers needed by the programme) and a lack of sufficient funding for the campaign.

In most communities, the programme was stuck at the stage of "preparing" the communities for testing.

But perhaps this is a blessing in disguise, because if the country is having problems mounting the testing programme, how could it possibly be up to the task of providing adequate support for all the people expected to test positive (about one quarter of the population in Lesotho is believed to be infected)?

Simply having ART available in the clinics is not enough — services must be able to capture and provide care for everyone who takes the test — to provide prevention support services to those who test negative, and perhaps most importantly, to refer those who test positive into care and treatment (regardless of their stage of disease).

Keeping people, who test positive but are not yet eligible for ART, in care is perhaps one of the greatest challenges confronting any testing programme.

WHO publishes draft guidance on routine PITC

Subsequently, WHO and the UNAIDS Secretariat posted draft guidelines on PITC for public comment from November 28 to January 31st. Indeed, they got a lot of feedback — from groups who believe that anything other than VCT is unethical and from human rights groups who fear that routine testing might lead to coercion and that human rights violations are likely (more below).

The WHO draft guidance recommended that the HIV test be made a standard part of medical care for all patients attending health facilities in generalized HIV epidemics.

In concentrated epidemics (where there is a high prevalence only among certain vulnerable groups) and low-level epidemics (where there is a lower prevalence in vulnerable groups), PITC should only be considered in certain settings (STI services, health services for most-at-risk populations, and antenatal, childbirth and postpartum services). PITC would be routine opt-out: "individuals must specifically decline the HIV test if they do not want it to be performed."

The United States and the United Kingdom have already instituted this approach, and the US is now attempting to implement routine HIV screening in all health care settings — unless the local prevalence of undiagnosed HIV infection has been shown to be under 0.1%.

However, although pre-test counselling would be simplified, before obtaining a patient's informed consent, the healthcare provider should first inform him or her about the potential adverse outcomes of testing, about what follow-up services are available in

the case of either an HIV-negative or an HIV-positive test result. Finally, the patient should be assured that refusing the test will not result in a denial of medical care.

The guidance set several conditions for the implementation of the recommendations.

First each country would have to adapt the recommendations to their specific setting in light of:

- The local epidemiology of the HIV epidemic
- Available resources
- The current standard of HIV prevention, treatment, care and support, and
- The adequacy of social and legal protections available to those living with, or at risk of exposure to, HIV.

Second and critically, implementation of PITC should only be undertaken in consultation with key stakeholders (presumably people living with HIV, and organisations representing marginalised and vulnerable groups).

Finally, the implementation should be phased, with close monitoring and evaluation to avoid negative outcomes, including stigma and discrimination, violence and unmet demand for treatment and other services.

The draft guidance also suggested several ways to create a more "enabling" environment for routine testing.

- There should be, if not yet universal access to ART, at least a clear national plan to achieve it in the near future
- A minimum set of HIV-related prevention, treatment, care and support services should be available, and
- Concurrent to implementing provider-initiated testing "efforts must be made to put in place a supportive policy and legal framework to maximise positive outcomes and minimise potential risks to the patient."

Criticism of the draft IPTC guidance

Proponents of VCT and human rights advocacy groups were quick to criticise the first draft. While some of the reactions struck this author as a bit knee-jerk, they have made some valid points that should not be casually dismissed.

"VCT is tested and effective"

Some have suggested that routine testing is a relatively unproven strategy but that "voluntary HIV testing programs...have been enormously successful."

It's true that there are, of course, some excellent VCT projects, that offer the highest calibre counselling and that successfully link patients to the appropriate care and support services. However, the coverage of these noble efforts is spotty at best, and the current capacity to scale them up limited.

Nevertheless, funding partners and governments should try to do more to make the most successful VCT programmes more accessible, and to increase public awareness of the need (and personal responsibility) to come in for testing.

However, the critics of more routine testing are kidding themselves if they think the quality of VCT in resource limited settings is always so consistently high — and when people go to VCT clinics, that there are never abuses of power or breaches in confidentiality, that people always have adequate support and counselling, that counselling greatly impacts behaviour, that women aren't still victims of violence when they disclose their results, that the referral linkages are always up to date and smoothly

functioning, and that people are never lost to follow-up when they get their results.

"There is no way that VCT programs in this country could be characterized as 'enormously successful'," said Chris W. Green, an AIDS Treatment Educator working with the Spiritia Foundation in Indonesia and a member of HATIP's advisory panel who is a long time proponent of VCT. However, years of work in the field have made him more circumspect.

"Even with current low rates of testing, the standard of counselling is often abysmal. Being a counsellor is a thankless task, poorly paid, often with little support from superiors, frequently a dead-end, with stress and burnout a very common risk."

"The problem is the level of sophistication we're asking from counsellors," said Dr. Venter. "They are seen as cheap labour — they are often slave labour — and they often lack the sophistication, the training that is required. They go through a 3-day training course and now they must deal with people's fertility issues and issues around stigma, which, highly trained psychologists can't deal with. I rant and rave about this all the time because it worries me a great deal."

Supporters of VCT need to remember that this counselling is not taking place in New York, London or Sydney. Counsellors in most resource-limited settings often have minimal training and inadequate remuneration.

Many people who have actually been tested in these settings (particularly those who test positive) can attest to this. This writer knows of many examples in southern Africa where people have been given horrible advice by their counsellors with disastrous consequences. Quality assurance is very rarely practised. But of course, this will likely be a problem in resource-limited settings regardless of the testing approach chosen.

In addition, Green points out: "Realistically, if we look at the number of people needing a test, there is no possibility that we can recruit, train, pay and retain sufficient numbers of counsellors. Nor can we provide enough supervisors, counsellors for counsellors, and trainers."

The risk of human rights being abused with more aggressive testing

Human rights groups quite correctly point out that some of the earlier attempts at mandatory testing were tied with efforts to deny the human rights of people with HIV/AIDS. More recently there have been reports of abuse associated with routine testing, such as in one country where test results are being required of any students applying for a school grants.

Furthermore, there have been many reports that 'opt-out' is illusory. Members of most vulnerable groups are much less likely to feel comfortable to 'just say no' to testing, while health care workers are much more likely to apply pressure to these people. In many cases, the patients will not understand what they are agreeing to and often they will not be given the option to decline unless they ask.

And even the appearance of giving certain oppressive governments the green light to routinely test marginalised and vulnerable groups for HIV should give one pause — particularly when members of such groups are subjected to imprisonment or government sanctioned police violence.

"There is risk that PITC or screening will be applied only to 'high-risk groups', adding to marginalisation, and potentially driving them away from health care services," notes Green. "If this occurs,

PITC could be counter-productive — for example, injecting drug users are often less than willing to seek health care."

However, it is not clear, as some critics assert, that the move towards more routine or universal testing is always tied with authoritarianism in the countries that are considering it, or as one group suggested, to the "faith-based" abstinence and be faithful prevention programmes being foisted on the continent by the PEPFAR programme.

With some exceptions, at most of the forums and meetings on the issue that this reporter has attended, most of the voices calling for increasing the numbers of people to be tested routinely have been clinicians, overwhelmed at the scale of sickness and death they must deal with on a day to day basis and hopeful that with the increasing access to ART, they can finally put a stop to much of it.

It is a good thing to be concerned with human rights in resource-limited settings but this must be balanced with a sense of urgency about the millions of people with HIV not receiving care (and dying) because they don't know their status. The status quo or waiting for VCT services to be scaled up everywhere is simply not acceptable.

"To me, to have free ARVs on the shelf (perhaps even expiring) while so many are unaware that they need them is a clear violation of human rights," said Green. "Although I have met many PLHIV in Indonesia who found out that they were HIV-positive without due process (sometimes even coerced), most are glad that they found out their status earlier than they otherwise would have."

At the same time, there is also a genuine risk that routine opt-out testing or universal testing will simply be put in place without any real efforts at all to truly introduce working support systems for those who need them after receiving their test results. And any testing policy that comes close to universal or routine must come after legal protections and operational safeguards are put in place to keep anyone from being "punished" for testing positive or for being targeted as a member of a marginalised group. Working on these protections "concurrently" may not be sufficient.

Unfortunately, until the world truly makes protecting African lives and human rights a global priority on the same scale as the so-called war against terrorism, in most settings, there will be no perfect solution, and some people will be hurt as an inevitable consequence of whichever testing modality choice is made.

In the end some sort of balance must be struck.

Do what is in the best interests of the patient

But perhaps the whole emphasis on the testing strategy is somewhat premature, and health care providers, community based organisations and advocates should primarily focus on protecting the patient and providing them with greater incentives to test (providing ART to those who need is just one aspect of this).

Before moving on to more aggressive testing, perhaps we need to ask ourselves: What systems or efforts are being established for making certain that appropriate post-test counselling is always available, and that referrals to appropriate services are in place wherever and however testing is performed?

What do we do to improve the quality of counselling, and increase the number of counselling staff available? How could expanded testing programmes provide the right amount of information to people during the testing process when human resources are so stretched?

People who test positive often suffer from debilitating depression, choose destructive coping mechanisms and are at a very real suicide risk — but mental health services in most resource

limited settings have long been neglected. What efforts are underway to change this in your setting? Would these changes be adequate to support thousands, or even millions, of people who suddenly learn their status?

It is fine to call for legal protections for people with HIV, but in how many resource-limited settings do they actually exist? What are the barriers to introducing such legislation? How can we leverage work and funding in this field to try to ensure that the rights of people with HIV, and of vulnerable groups, are protected?

There should always be ongoing operational research evaluating testing programmes — beginning with existing VCT services and moving on to whatever other testing approaches are adopted or experimented with. These should look at overall health and well-being outcomes for the communities involved — not just at the number of people tested, incidents of abuse or how many people went onto treatment. Overall outcomes from VCT or routine testing programmes should be compared directly to each other — at present there is little to no comparative data to guide policy.

Finally, in some settings, such operational research or even quality improvement programmes look suspiciously like criticism of the government programme — and this can pose a problem in countries that view their programmes as a source of national pride. How do we encourage policy makers and programme managers to conduct regular, honest, and transparent appraisals of their programmes?

“We need to find the least bad way to achieve the objective,” said Green. “On the whole, I’m on the side of more aggressive testing. We have to find a better balance between protection of the right to testing with due process and access to treatment.”

Dr. Venter isn’t entirely sure whether most people really want these choices.

“One of the things I sometimes wonder about is whether or not it’s a westernised thing — this worry about consent. I do sometimes think the language used is met with bewilderment by patients,” he said. “At the recent PEPFAR consultation, Dr. Ernest Darkoh [who was involved in the Botswana government programme] used this amazing quote: ‘The traditional healers kick our ass and it’s because to them there’s no grey.’ It’s black and it’s white; it’s like: ‘You must do this. This is what you must do; you must follow these tablets, you must have these tests and you will get better.’ None of this: ‘...ooh, are you ready, prevarication.’”

“The traditional healer takes control in a situation where people are feeling powerless and actually takes on the decision making for that person and I think patients actually want that. I think some don’t, but most do. I always think that when I’m sick, I just want you to give me the sodding tablets. Don’t sit and negotiate with me. Tell me what’s the best for me. Tell me if I’ve got other options and if I need to make that decision, then I’ll come to that decision myself. But by and large, give me a decision. Don’t sit there and try and negotiate with me when I’m feeling sick.”

“I think those sort of issues aren’t debated enough. Those around how much patient autonomy do they actually want, how much do you hand to them and how much of it actually scares the hell out of people and how much of it’s culturally based. That’s what scares me. I think that what works for me, may not work for the person in deep Hillbrow, may not work for rural Limpopo; may not work for Zimbabwe and I think that there’s not enough discussion of that.”

Green believes the empowerment to make such decisions — and to make more services available — may only come after more routine testing.

“In the end, perhaps we must come back to reality. The services we need are unlikely to be in place in the next 5-10 years. Indeed, what has driven much of the development of such services as now exist is the activism resulting from increasing numbers aware of their infection demanding services. Recall that if we had waited until everything was in place before starting 3 by 5, we’d still be just talking. More people aware of their infection, by whatever means, will drive demand — and provide the human resources to support some of it. It will help ‘normalise’ HIV more quickly, and thus encourage more HIV-positive people with professional capabilities (who are currently unwilling to be identified) to contribute to the response.”

“We should strive to improve, but the rights of people to be aware of their infection should be given greater weight than their right to ‘due process’ in testing.”

One positive step: the GNP+ programme

The Global Network of People living with HIV/AIDS (GNP+) GNP+ is currently working on a multi-year programme for scaling up initiatives to strengthen and support testing programmes, led by people living with HIV and vulnerable groups. The focus will be on ensuring that the benefits of testing and knowing one’s status greatly outweigh the risks — in other words, that high quality services for people who test are in place. This in and of itself should increase demand.

GNP+ plans to actively engage affected communities through multi-stakeholder consultations led by people living with HIV and vulnerable groups in order to develop schedules for scaling up community based services in addition to testing and which integrate the health sector working towards targets for universal access.

These consultations will begin in five countries in 2007, and GNP+ hopes to expand this to 25 countries within 3 years. The programme will include an element of capacity building of people living with HIV and vulnerable groups, to ensure that their voices are heard at community, national and international levels.

A new and excellent resource

The International HIV/AIDS Alliance has produced a new resource “Let’s talk about HIV counselling and testing - Facilitators’ guide” (see <http://www.aidsalliance.org/sw37361.asp>) to help non-governmental organisations (NGOs), community based organisations (CBOs) and other civil society organisations in developing countries help mobilise communities for HIV counselling and testing (HCT).

The guide covers different aspects of HCT and includes participatory activities to carry out with NGO/CBO staff. The resource starts out by providing basic information about testing, and then tries to get participants to think critically about the advantages of and barriers to HIV counselling and testing; issues around stigma, discrimination, and confidentiality; the different medical, social, psychological and economic needs of people who test either negative or positive for HIV.

Some sections can be used to do local situation assessments or analyses within the community, to understand, for example, what services exist, what awareness there is of these services, what are the issues regarding accessibility and quality of counselling to locally provided services, and what gaps remain between the service provided and the needs of those being tested.

For example, the following section excerpted from the guide, tries to get people to think about the quality of services and support available before referring someone to a site for testing.

- Is the service 'person-centred', based on meeting the person's particular needs?
- Does the service provide ongoing follow-up and support? It is important to keep in mind that HIV counselling and testing is never an end in itself. If referral is done properly during post-test counselling, the client who has been tested will be encouraged to seek further information and support – whether they are HIV positive or negative. This will depend on the needs of the client and what is available locally. It might include:
 - ongoing counselling provided by trained counsellors, including information about HIV, healthy living, etc.
 - moral support from other people living with HIV (peer support)
 - moral support from others who have tested for HIV (for example, post-test clubs)
 - psychological support provided by health professionals (for example, psychotherapy)
 - spiritual support
 - social support
 - income-generating activities
 - medicines for pain, OIs (including TB treatment and prevention), and ARVs
 - alternative therapies, including traditional remedies for the treatment of some OIs

- STI treatment and prevention
- condoms, information about safer sex.

Finally, the final section of the guide offers ideas and provides cases studies describing activities that NGOs and CBOs can carry out in community settings when time is limited and contact with a community group is restricted.

Some other resources:

<http://www.gnpplus.net/cms/index.php>

<http://hrw.org/pub/2007/hivaid/hrwWhoGuidance.pdf>

<http://www.who.int/hiv/topics/vct/en/index.html>

Policy statement on HIV testing, UNAIDS/WHO, 2004, (http://data.unaids.org/una-docs/hivtestingpolicy_en.pdf)

Handbook for legislators on HIV/AIDS, law and human rights, UNAIDS/IPU, 1999(http://whqlibdoc.who.int/unaid/1999/UNAIDS_99.48E.pdf)

about HATiP

A regular electronic newsletter for health care workers and community-based organisations on HIV treatment in resource-limited settings.

The newsletter is edited by Theo Smart (Cape Town) and Keith Alcorn, NAM's Senior Editor (London).

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