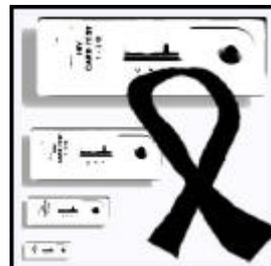


Different models of HIV-testing

What are the considerations in South Africa?

AIDS Law
Project
Discussion
Paper

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Different models of HIV-testing

What are the considerations in South Africa?*

At least, in South Africa, many do not come forward until they are seriously unwell and therefore less amenable to treatment by the available therapies. It is in these circumstances that consideration must be given to whether past strategies of pre-test voluntary counselling and testing need to be modified or qualified in various ways in order effectively to 'scale up' the testing so as to bridge the reticence and impediments and to get the ARVs quickly to those who need them.

- Michael Kirby¹

To translate research advances into public health benefit will require people who are infected to be diagnosed early. To achieve this, HIV/AIDS needs to be normalised and its diagnosis considered a task of all medical practitioners, even if subsequent management needs to be supervised by specialists.

- Kevin De Cock & Anne Johnson²

The conditions under which people undergo HIV-testing must be anchored in a human rights approach which protects their human rights and pays due respect to ethical principles.

- UNAIDS/WHO Policy Statement on HIV Testing³

Introduction

Human Rights approaches should be based on facts. Important facts that pertain to the AIDS epidemic in South Africa in 2006 are the following: AIDS is now a medically manageable condition. Secondly, while public sector roll-out of ARVs is slow and uneven, AIDS treatment is becoming increasingly more accessible to people living with HIV/AIDS (PWAs) in South Africa. Thirdly, the overwhelming majority of people with HIV, and who are therefore at risk of AIDS, do not know that they have HIV. Lastly, stigma not only inhibits access to treatment, but HIV-testing itself. Human rights approaches to HIV-testing practices should therefore aim to minimise stigma.

* I would like to thank Edwin Cameron, Mark Heywood and Sara Nam for comments on earlier drafts of this document.

¹ M. Kirby "The never-ending paradoxes of HIV/AIDS and human rights" *African Journal of Human Rights* 2004 Vol. 4 No 2 163-180:176.

² KM De Cock and AM Johnson "From exceptionalism to normalisation: a reappraisal of attitudes and practice around HIV testing" *British Medical Journal* 1998 Vol.316, 24 January, 290-293:292.

³ UNAIDS/WHO Policy Statement on HIV Testing, June 2004, p.1.

The commitment to providing treatment to PWAs who need it world-wide, most notably in the form of the World Health Organisation (WHO) ‘3by5’ initiative⁴, PEPFAR funds⁵ and the UNGASS ‘Declaration of Commitment’⁶, has led the international AIDS community into lively debate about the most appropriate and most effective forms of HIV-testing. While there is agreement that the traditional model of Voluntary Testing and Counselling (VCT) has not reached enough people, there is disagreement about the reasons for this failure. While both human rights advocates and public health practitioners agree that new directions for HIV-testing is essential to increase the number of people who access, and who have access to, HIV-testing and thus ultimately to life-saving treatment, there is some disagreement about the form this would take. The debate has mainly concentrated on the “opt-in” and “opt-out” forms of HIV-testing that are associated with routine testing, and in particular the nature of pre-test counselling (if any) and the type of consent required.

This paper will consider different models of HIV-testing that are currently under discussion, with a particular focus on the potential advantages and disadvantages of the “opt-out” routine testing model that has been proposed in draft format by the WHO and UNAIDS⁷ and to some extent by the South African Department of Health. The paper will begin by setting out the historical rationales for a VCT approach to HIV-testing and then briefly look at the South African context in relation to HIV-testing and treatment. Due to the fact that a number of terms are often used interchangeably - with resultant confusion - to describe the different formats of HIV-testing, this paper will also discuss the different models of HIV-testing as defined by the WHO in order to frame the discussion on routine testing.

AIDS Exceptionalism and its relevance

With the advent of HIV/AIDS in the 1980s, a number of characteristics set it apart from other epidemics and communicable diseases. HIV was not contagious, but could be

⁴ WHO “Treat 3 Million by 2005 Initiative” Geneva, 2003. The WHO and UNAIDS global initiative to provide antiretroviral therapy to 3 million people with HIV/AIDS in developing countries by the end of 2005. Available:

<http://www.who.int/3by5/publications/documents/en/3by5StrategyMakingItHappen.pdf>

⁵ President George W. Bush’s Emergency Plan for AIDS Relief (PEPFAR) intends to channel \$15 billion towards HIV/AIDS programmes in more than 120 countries.

⁶ The UNGASS “Declaration of Commitment” contained a number of goals on care, treatment and support. See UNGASS “Declaration of Commitment” United Nations Special Session, 15-27 June 2001, Available http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf

⁷ UNAIDS/WHO “Provider-initiated HIV Testing and Counselling in Clinical Settings: Operational Recommendations” First Draft for Comment, 27 June 2006.

transmitted in a limited number of ways – most notably through sexual intercourse and the sharing of needles by intravenous drug-users. HIV/AIDS has no cure, and in the 1980s and early 1990s, many people with HIV/AIDS would succumb to AIDS-related illnesses within a few years of seroconversion. The ever-increasing knowledge of treating opportunistic infections, the greater availability of medicines and the development of anti-retrovirals (ARVs) have greatly mitigated the morbidity and mortality associated with HIV/AIDS – especially so in resource rich countries where treatment and good quality health care services are more easily available. But the death, suffering and despair that characterised the epidemic especially in its early years as well as the epidemic’s exponential growth, gave rise to a potent assortment of fear, stigma and discrimination. While a number of groups advocated a traditional public health response to the epidemic,⁸ HIV/AIDS became known early on as an exceptional epidemic – so-called “AIDS exceptionalism” - and one that required an approach steeped in human rights and ethics. Kirby describes it in the following way:

From the start, HIV/AIDS has not been like any other epidemic. The numbers of people infected were far too numerous to warrant the traditional approach of quarantine. Furthermore, the long period of latency of the virus and the limited modes of transmission made such an approach disproportionate. The absence of a rapid cure and the failure to develop speedily a safe and effective vaccine has meant that HIV/AIDS is not susceptible to the usual medical or public health responses, used in the past in challenges of this kind. Moreover, the principle modes of transmission – penetrative sexual activity and injecting drug use (commonly involving stigmatised groups in the community: sex workers, men who have sex with men, and drug users), together with high initial levels of mortality and widespread community fear have made HIV/AIDS a most troublesome problem.⁹

This explicitly human rights approach to this “most troublesome problem”, Kirby termed in earlier work as the “AIDS paradox”¹⁰: the most effective way to protect the uninfected and to curb the spread of HIV/AIDS, is to protect those already infected with HIV/AIDS and those most in danger of contracting it. He noted that he characterised it as a paradox as many people’s first reaction to the epidemic was in fact to demand that the uninfected be protected from the infected.

⁸ Bayer describes traditional public health responses thus: “[Public health laws] provided a warrant for mandating compulsory examination and screening, breaching the confidentiality of the clinical relationship by reporting to public health registries the names of those with diagnoses of “dangerous diseases,” imposing treatment, and in the most extreme cases, confining persons through the power of quarantine.” Bayer R. “Public health policy and the AIDS epidemic: an end to HIV exceptionalism? *New England Journal of Medicine* 1991, 324:1500-1504, p.1500.

⁹ Kirby (2004) *op cit* p.164

¹⁰ M. Kirby, “AIDS and the Law” *South African Journal on Human Rights* 1993, 9(1): 1-21

The human rights approach to HIV/AIDS has led to a novel methodology in testing a person's HIV status. VCT emphasised the voluntary nature of the test (the client or patient generally had to request the test) and this was a direct response to the calls for the mandatory testing of high risk groups in the beginning of the epidemic.¹¹ VCT also called for pre- and post-test counselling, express and informed consent that an HIV-test will be conducted on the patient, and assurances of the confidentiality of the test result.

With the advent of treatment, a number of authors (including Kirby himself) have questioned the ongoing relevance and appropriateness of "AIDS Exceptionalism". Cameron illustrates how the rigorous requirements of VCT is an example of AIDS Exceptionalism in the following way:

These [VCT] protections treated the disease as exceptional, because it was exceptional – not only because of the level of stigma that surrounded it, but because no medical treatment was available for it.

But the world has changed. And the epidemic has changed. The protections were designed for a world in which stigma caused death, and in which protection from its effects could often be secured only by protecting the patient from unnecessary HIV testing, whose only product, all too often, was victimisation, ostracism and discrimination. [...]

Where effective medical management of the disease can be offered to patients, this suggests a new and disquieting paradox: that the exceptionalisation of HIV, designed to protect from needless discrimination, may constitute a barrier to diagnosis and treatment.¹²

Proponents of the normalisation of AIDS¹³ argue that it will decrease the stigma associated with the epidemic, remove barriers to testing, increase access to treatment and change societal perceptions of HIV/AIDS. Bayer summarises some of these arguments in this way:

¹¹ Naidoo writes: "[VCT] Counsellors are trained to assume a neutral role in this process, irrespective of the reason that the individual presented for a test. The over-emphasis of the voluntary nature was partly in response to the call for mandatory testing early in the epidemic. This may have been appropriate in view of high levels of stigma and discrimination and limited treatment options in the 70's and early 80's" P. Naidoo "Voluntary Counselling and Testing" *AIDS Analysis Africa* May/June 2006, p.2

¹² E. Cameron "Normalising Testing – Normalising AIDS" Forum Lecture, University of KwaZulu-Natal, Durban, Ronald Louw Memorial Campaign: 'Get Tested, Get Treated', 4 May 2006, Available: <http://www.nu.ac.za/ccs/files/LouwRonaldMay06.pdf>

¹³ De Cock and Johnson give the following definition to the normalization of AIDS: "Normalisation then refers to treating HIV/AIDS more like other infectious diseases for which early diagnosis is essential for appropriate therapeutic and preventive measures, within the requirements of informed consent and respect for confidentiality" De Cock and Johnson *op cit* p.290

According to advocates of change, the transformation of HIV disease into a complex chronic condition requiring long-term, ongoing clinical management means that the limits imposed when medicine had little to offer have outlived their justification. Proponents argue that prevailing requirements impeded wide-scale testing because they are burdensome and time-consuming. Furthermore, they relieve physicians of an obligation to offer testing.¹⁴

Frieden and others argue for an explicit return to traditional public health principles in an effort to normalise AIDS:

Now, given the availability of drugs that can effectively treat HIV infection and progress on antidiscrimination initiatives, perhaps society is ready to adopt traditional disease-control principles and proven interventions that can identify infected persons, interrupt transmission, ensure treatment and case management, and monitor infection and control efforts throughout the population.¹⁵

Some human rights advocates have expressed concerns about the movement towards normalisation. A symposium bringing together a number of human rights and AIDS advocates to discuss new directions in HIV and human rights, raised concerns about the call for an end to AIDS exceptionalism. They noted that it may be premature as AIDS was not yet a “normal disease” and that it may come at a high cost to PWAs - especially women. They also questioned whether a return to traditional public health principles might not hide the broader concerns of PWAs.¹⁶

¹⁴ R. Bayer and AL Fairchild “Changing the Paradigm for HIV Testing — The End of Exceptionalism” *New England Journal of Medicine* 2006 355:647-649, p.649

¹⁵ TR Frieden, M Das-Douglas, SE Kellerman and KJ Henning “Applying Public Health Principles to the HIV Epidemic” *New England Journal of Medicine* 353:22, 1 December 2005, 2397-2402: 2397

¹⁶ Canadian HIV/AIDS Legal Network, Centre for Health and Gender Equity and Gay Men’s Health Crisis “Outcomes of the Symposium on HIV Testing and Human Rights” Montreal, 24-25 October 2005. The section of the briefing paper on the normalization of AIDS reads as follows: “HIV-related disease is not (yet) a “normal” illness. Is it putting the cart before the horse to propose normalization through approaches to a single intervention (i.e., HIV testing) that may come at a high cost to people living with HIV, the burden of which will be borne disproportionately by certain groups of people living with HIV (e.g., women)? Could other approaches to destigmatizing HIV — such as appropriate social marketing of testing, support for people living with HIV, and leadership by political leaders as well as people living with HIV — be more appropriate and effective? Is normalization a way to introduce a return to a more traditional notion of infectious disease control, in which the broader concerns of individuals affected by HIV are seen as unimportant and thus need not be addressed by HIV programs or governments? Or is normalization a recognition that the risk-benefit ratio has evolved with the advent of antiretroviral treatment (ART)? Should more routine approaches to HIV testing necessarily be linked to ART access or is it enough on the risk-benefit scale if those who test HIV-positive may not have immediate ART access but have access to quality services providing care and support, including, nutritional counselling and support, and psychosocial support through health services and community-based mechanisms?” p.4

Proponents of the normalisation of AIDS have pointed out that the exceptionalisation of AIDS has had a powerful and enduring effect on health care systems. De Cock and Johnson write

Though we believe that more extensive HIV testing is necessary, we acknowledge that the exceptional status of HIV/AIDS has enhanced communication between doctors and patients and has made medicine less formal. Autonomy has been strengthened and patients have become more involved in decisions about their own care. Individuality has been more readily acknowledged, respect for informed consent and confidentiality has increased, and patient advocacy has emerged as a force of change.¹⁷

From the above it is clear that the new availability of treatment for AIDS and the potential for radically scaling up its accessibility has fundamentally changed the way the epidemic is perceived. This dramatic shift in perceptions has given rise to a call for a new approach to HIV/AIDS – one in which there is an emphasis on scaling up the number of people who know their HIV status. Thus, the aim of scaling up of HIV-testing is ultimately to put those who are newly-diagnosed in a position to better manage their HIV status and to enable them to access treatment when it is medically appropriate. The remainder of this paper will be devoted to a discussion of strategies associated with this new approach against the South African background.

The South African Context

The findings of South Africa's largest household survey again confirm one of the realities of the South African epidemic – that there is a “large number of people who are HIV positive, but do not know their status”.¹⁸ Indeed the survey found that 69.7% of respondents in the survey had never had an HIV-test before. More worrying is the fact that a high HIV prevalence rate was found in people who considered themselves to be at low risk of infection.¹⁹ The absence of testing cannot be correlated to lack of knowledge of VCT facilities, as the survey found that more than three quarters of respondents knew of a VCT facility in “a place nearby”.²⁰

¹⁷ De Cock and Johnson *op cit* p.292

¹⁸ O Shisana, T Rehle, LC Simbayi, W Parker, K Zuman, A Bhana, C Connolly, S Jooste, V Pillay et al “South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2005” 2005 Cape Town: HSRC Press, p.xxxii.

¹⁹ *ibid*, p.78

²⁰ *Ibid*, p.79

These findings need to be read in combination with the fact that there are close to 6 million people with HIV/AIDS in South Africa²¹ and that more than 837 000 people require anti-retroviral treatment at present²² - many of whom may not know, or even want to know, that they are HIV-positive or indeed that they have AIDS.

It would be useful to derive statistics on VCT as an indicator of how many people know their HIV status. Unfortunately meaningful statistics on VCT in South Africa is difficult to obtain. In April 2006, the AIDS Law Project approached all the provincial departments of health as well as the National HIV/AIDS Directorate and requested information on the number of people who accessed VCT services in 2004 and 2005 in the provinces, the monitoring and evaluation mechanisms in place and the budgets allocated to VCT. After lengthy and on-going correspondence with all the departments, six responded at the time of writing. The data of these six provinces is summarised in Appendix A. Regrettably provinces provided data for different time periods, which makes useful comparison impossible.

At the time of the UNAIDS “High Level Meeting on AIDS” to assess the progress that countries have made in fulfilling their commitments under the United Nations General Assembly Special Session (UNGASS) ‘Declaration of Commitment’, the South African department of health released the following statistics on VCT:

- Health facilities providing voluntary counselling and testing (VCT) have doubled from 1 500 in 2002/03 to 3 700 in 2004/05.
- The number of people **counselled** for testing in the public sector rose from 413 000 in 2002/03 to 691 000 in 2003/04 and 1,3 million in 2004/05.
- The total number of people **tested** during 2003/04 was 511 843 compared with 247 287 in the previous year.²³

²¹ The 2005 HIV antenatal survey estimated that there were 5.54 million people living with HIV/AIDS in South Africa in 2005. Department of Health “National HIV and Syphilis Prevalence Survey, South Africa, 2005”, Pretoria, 2006.

²² The WHO estimated that 837 000 PWAs required treatment at the end of 2004. Clearly this figure would have increased subsequently. WHO Country Profile for HIV/AIDS Treatment Scale-up: South Africa, June 2005

²³ South Africa’s Comprehensive Plan – A Fact Sheet, May 2006. Available: <http://www.saembassy.org/SOUTH%20AFRICA%20COMPREHENSIVE%20HIV%20AND%20AIDS%20PROGRAMME.htm>

Unfortunately these statistics do not include information on gender, age or geographical location. Nor do they indicate how many people returned for their test results. Indeed there is no analysis. It also excludes information on testing done in the private sector and people who utilise home HIV-testing. It therefore does not provide an adequate reflection of the level of HIV status knowledge in South Africa. In the absence of such data, it is almost impossible to measure the impact of VCT in South Africa, and to ascertain how many people know their HIV status.

In light of this, it is thus important that extensive nation-wide research and assessment are conducted into HIV-testing take-up, barriers to testing and quality of services. While preliminary research has shown a correlation between an increase in the uptake of VCT services and the availability of ARVs,²⁴ more research needs to be done to understand how people make decisions about HIV-testing: what they regard as important incentives and whether a critical mass of people would be motivated to test if treatment becomes readily accessible.

From the Department of Health statistics above it would seem that the utilisation of VCT services in South Africa has increased over the last three years. Yet, it is clear that current initiatives are only reaching a fraction of people in need of it. It should be stressed though that the need for more research should not stand in the way of implementing immediate changes to our approach to HIV-testing.

New draft HIV-testing paper

In October 2006, the Department of Health compiled a draft document on HIV-testing entitled “The National Policy on Counselling and Testing for HIV in South Africa”²⁵.

This policy signifies a clear change from the “National Policy on Testing” of 2000,²⁶ which is based almost exclusively on the VCT model. The draft policy makes provision for the offer of counselling and testing to “any person motivated to know their HIV status who are 14 years of age and above” and notes that the “counselling and testing

²⁴ C Mfundisi, N Chiranjan, C Rodrigues, L Kirchner, P Bock and L Myer “Availability of antiretroviral therapy is associated with increased uptake of HIV testing services” *South African Medical Journal* July 2005, Vol.95, No.7, 483-485

²⁵ Department of Health “The National Policy on Counselling and Testing for HIV in South Africa” Draft Document, October 2006, Copy available: www.alp.org.za

²⁶ Department of Health “National Policy on Testing” August 2000. Copy available: <http://dedi20a.your-server.co.za/alp/images/upload/3rdAids%20finalss%20append.pdf>

must be informed, voluntary and consented”.²⁷ Under the heading “Routine Offer or Standard Care”, the draft policy provides that “Health providers recommend HIV counselling to all clients on a routine basis to ensure that all clients who would benefit from counselling and testing receive these services”.²⁸ Groups that will be targeted by the routine offer of an HIV-test also include clients with STIs or TB, people with more than one sex partner, vulnerable groups (such as commercial sex workers, migrant workers, substance users, migrant workers, prisoners and long distance truck drivers), couples considering having children and all patients who attend primary health care services. It is clear that the Department is contemplating a more proactive and wide-ranging form of HIV-testing and this should be supported and encouraged. While the draft document has a number of problems²⁹, it is vital that the Department finalises the draft policy as a priority, but with wide consultation.

Different models of HIV-testing

At this point it will be useful to summarise the main models of HIV-testing. The WHO set out four types of testing:³⁰

1. Voluntary Testing & Counselling

This form of HIV-testing is client-initiated and contains pre- and post-test counselling. UNAIDS/WHO notes that pre-test counselling can be provided in a group situation, but that post-test counselling should be done on an individual basis.

²⁷ Department of Health “The National Policy on Counselling and Testing for HIV in South Africa ” *op cit* p.17.

²⁸ *ibid*

²⁹ Some problematic areas include:

- It is not clear from the current draft if the form of HIV-testing contemplated will be in the form of “opt-in” or “opt-out” testing;
- It would appear that counselling is compulsory and that the client will not be able to have an HIV-test if s/he declines counselling;
- A professional health worker (trained to work with blood products in terms of the Human Tissue Act of 1983) has to be available during operating hours of the health facility to conduct testing for rapid tests, PCR and ELISA tests. This precludes counsellors from conducting finger-prick tests;
- The notion of “shared confidentiality” has to be expanded and be clearly distinguished from Botswana’s model of “shared confidentiality” (see the section on Botswana below); and
- The draft policy is not clear about the role that VCT will play in the model proposed.

³⁰ This discussion is based on “UNAIDS/WHO Policy Statement on HIV Testing”, June 2004. Available: http://www.who.int/rpc/research_ethics/hivtestingpolicy_en_pdf.pdf#search=%22%E2%80%9CUNAIDS%2FWHO%20Policy%20Statement%20on%20HIV%20Testing%E2%80%9D%22

2. *Diagnostic [or symptom-responsive] HIV-testing*

This form of HIV-testing is conducted when a patient shows symptoms that are associated with AIDS-related illnesses. UNAIDS/WHO notes that HIV-testing is included in the routine management of TB patients.

3. *Routine offer of HIV-testing by Health Care Providers*

A routine offer of an HIV-test is made to all patients:

- a) Who have a sexually transmitted infection (STI)
- b) Who are pregnant; and
- c) Who are seen in clinical and community based health settings where the HIV prevalence levels are high and where ART is available.

The conditions of counselling, consent and confidentiality are applied, but pre-test counselling only includes a minimum amount of information to warrant informed consent. UNAIDS/WHO recommends the following minimum information for informed consent:

- The clinical benefit and the prevention benefits of testing
- The right to refuse
- The follow-up services that will be offered, and
- In the event of a positive test result, the importance of anticipating the need to inform anyone at ongoing risk who would otherwise not suspect they were being exposed to HIV infection.

UNAIDS/WHO notes that under models 2 and 3, patients still have the right to refuse testing – that is to “opt out” of testing

d) *Mandatory testing*

People are tested for HIV without their consent, without counselling being provided or in some instances without their knowledge. This form of testing is also often described as compulsory or involuntary testing. Most international agencies reject this form of HIV-testing and describe it as unethical, except in cases of HIV screening of blood and organ donations.

UNAIDS/WHO underlines that all HIV-testing should be conducted by respecting the so-called “3Cs”: counselling, consent and confidentiality. It is noticeable though that the

way that UNAIDS/WHO sets out the different models of HIV-testing does not distinguish particularly well between models 2 and 3 – diagnostic testing and routine offer of an HIV-test. It should also be noted that some proposals make a further distinction between “opt-in” routine testing and “opt-out” routine testing. The former model includes an offer of an HIV-test which the patient actively has to agree to, while the latter model usually assumes that the patient accepts the HIV-test unless s/he explicitly declines the test. UNAIDS/WHO has recently resolved to revise their position on VCT – “the philosophical and ethical underpinnings of VCT are currently being revised in the light of new treatment possibilities”.³¹ The next section will deal with their draft proposals after assessing the philosophical underpinnings and current research of the VCT model.

New Approaches

The urgent need to “scale up” treatment for the massive population of PWAs who are desperately ill or will become desperately ill in South Africa and in other middle or low income countries, has caused a number of international bodies, medical practitioners and AIDS activists to call for a dramatic “scaling up” of HIV-testing. HIV-testing is naturally seen as a “critical gateway” to access treatment and support, and various authors have proposed a rigorous reconsideration of HIV-testing principles, ethics and procedures to increase the number of people who know their HIV status, as well as how to manage their status – whether positive or negative.

An individual’s knowledge of her HIV status is of course not only vital for the effective management of her HIV-disease progression, but also for national prevention programmes. The WHO enumerates the following advantages to knowledge of HIV status:

Knowing their status enables

Individuals to:

- Initiate or maintain behaviours to prevent acquisition or further transmission of HIV
- Gain early access to HIV-specific care, treatment and support
- Access interventions to prevent transmission from mothers to infants

³¹ UNAIDS Policy Position: HIV testing and counseling Available: <http://www.unaids.org/en/Policies/Testing/default.asp>

- Better cope with HIV infection
- Plan for the future

And helps their communities to:

- Reduce the denial, stigma and discrimination that surround HIV/AIDS
- Mobilize support for appropriate responses³²

While the advantages of knowing one's HIV status are clear in theory, it has not translated into people streaming to VCT clinics to ascertain their HIV status, nor to do so at regular intervals. While the lack of hard data on VCT in South Africa is acknowledged, a brief assessment of the main form of HIV-testing in South Africa based on available research and critiques will be useful, before studying new approaches.

An assessment of the VCT model

Some authors have questioned whether the rigorous requirements of VCT – within the context of treatment - may not in fact assist in creating or reinforcing the stigma that attaches to HIV/AIDS. Cameron asks the following challenging questions:

I ask us to reflect on something those who consider themselves rights-conscious may find harder to face: the question whether the human rights protections we have helped erect around AIDS – and in particular in medical diagnosis – contribute to and reinforce the internal dimensions of stigma [...]

[...]This is because many people, offered the choice of diagnostic procedures whose exceptional and unusual nature is emphasised, prefer not to be tested. When they visit a healthcare facility, they are not simply and merely tested for HIV. The diagnosis of the disease is treated as exceptional, and is hedged around with fuss and palaver and hullabaloo, including the requirement of express and specific consent, and the insistence on pre-test counselling.

These safeguards are intended for the protection of people with HIV; but today I suggest that they also serve to reinforce the inner fears and dread – the inner sense of self-contamination – of those who suspect they may have HIV. All too often those safeguards accentuate the inner disavowal of entitlement to betterment. People shy away from being tested because the requirements relating to consent and counselling accentuate the differentness and distinctness and horror of AIDS. They emphasise to the patient that this disease is exceptional, abnormal, unusual.

As a result, rather than consenting to being tested, many shy away. They prefer to ascribe their symptoms to causes other than HIV, when all too often the routine administration of a test will confirm the opposite, and will open the way to effective management of their condition.³³

WHO acknowledges that many potential clients might view the counselling requirements as onerous and therefore barriers to testing: “One-to-one counselling and the time

³² WHO “The Right to Know – New Approaches to HIV Testing and Counselling” 2003 WHO/HIV/2003.8, p.1

³³ Cameron *op cit*

required to provide it are possible disincentives for people who wish to be tested on a more routine and perhaps less conspicuous basis”.³⁴ Frieden and others regard this as “missed opportunities to diagnose, treat, and stop the spread of HIV infections”.³⁵ These sentiments are echoed by a doctor in Botswana. Dr Howard Moffat who is the medical superintendent of the biggest hospital in Botswana, Princess Marina Hospital observed the following about the application of the VCT model in Botswana: “In fact, we found that people who had not made their minds up quite often were definitely against [HIV-testing] once the pretest counselling was done. [...] I think the medical profession itself...played a major role in creating this fear of AIDS and this quite irrational reluctance to be tested.”³⁶

This phenomenon is possibly borne out by South African experience. If the May 2006 data set of VCT services provided by the Department of Health is scrutinised, the discrepancy between the number of people who accessed counselling, and who in fact tested for HIV is conspicuous:

- In 2002/2003, 413 000 people were counselled, and only 247 287 tested for HIV. This means that potentially 165 715 people did not get tested after counselling; and
- In 2003/2004, 691 000 people were counselled of which only 511 843 tested, leaving a potential of 179 157 people who did not.

It is hard to ascertain why a substantial number of people did not follow-through and test for HIV. It could be postulated that after pre-test counselling, a number of clients may have realised that they were still in the window-period and that there would be little point in testing. Or, might it be that the hospital or clinic had run out of testing kits or staff to administer the tests? More worrying is the possibility that a client, who voluntary elected to attend VCT in order to learn her HIV status, was dissuaded by the counselling session or the counsellor. This amounts to a disquieting number of missed opportunities of people learning their status. An alternative view might well be that a number of people who attended VCT services were unsure whether they wanted to test, and that a substantial portion (60% in 2002/03 and 74% in 2003/04 – a marked increase) decided to take the test after pre-test counselling. Unfortunately the lack of research in this area

³⁴ WHO(2003) *op cit* p.2

³⁵ Frieden *et al op cit* p.2397

³⁶ A Zavis “Botswana adopts radical approach to HIV” Associated Press, 29 January 2006, Available: <http://ww2.aegis.com/news/ap/2006/AP060140.html>

means that one can only hypothesize about the state of mind of people who attend VCT services.

Knowing one's own positive HIV status or those of people close to one, may have a favourable effect on the individual's stigmatising attitudes as well as risk-taking behaviour. A South African study shows a potential relationship between people who do not test for HIV and high-risk behaviour, as well as stigmatising behaviour:

Analyses showed that people who were not tested for HIV were more likely to have never used a condom and were more likely to have used injection drugs, both indicating potential higher risk among untested people. Participants who had been tested were, however, significantly more likely to have been diagnosed with an STI. [...] Comparisons between HIV testing history groups on attitudes towards HIV testing showed that participants who had not been tested held significantly more negative HIV testing attitudes than participants who had been tested after controlling for age, sex, education, and survey venue. Individuals who had not been tested for HIV were significantly less likely to view beneficial outcomes from testing, more likely to perceive adverse testing outcomes, and more likely to endorse test avoidance”³⁷

This study also found that high levels of AIDS knowledge were not associated with HIV-testing. While this study cannot be generalised to South Africa as a whole, it does draw attention to the fact that the people most in need of testing, and those who contribute to levels of AIDS stigma in a community, are possibly the least likely to test. This is despite the fact that there may be high levels of knowledge about HIV/AIDS. This provides an important lesson for the messages that should be associated with HIV-testing and encouraging people to learn their status.

Following research in the USA, it could also be postulated that this group of people are responsible for a substantial amount, if not most, of new infections. The Centres for Disease Control (CDC) found that PWAs in the USA “reduced the number of unprotected serodiscordant sex they had by 68% after diagnosis. This led them to believe that the 25% of people who do not know their HIV status in the USA contributed about 50% of infections”.³⁸ It is also important to note the gender dimensions of VCT - some studies have found that only 21% of all patients accessing

³⁷ SC Kalichman and LC Simbayi "HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa" *Sexually Transmitted Infections* 2003;79:442-447

³⁸ Mastro *op cit*

VCT are men.³⁹ It is clear that the vast majority of people who learn their status through VCT are women, and that men are much less likely to seek testing on their own accord.

Rennie and Behets write the following about VCT's emphasis on self-presentation for a test:

To sharply increase the number of people being tested for HIV, a departure from the traditional voluntary counselling and testing (VCT) model would be required. As the name suggests, VCT involves people self-presenting for testing at their local medical facilities if they believe they have been exposed to HIV. Poor uptake of VCT, despite decades of AIDS education campaigns, is reflected in estimates that the vast majority (<90%) of HIV-positive people in low-income countries do not know they are infected. The successful meeting of treatment targets will require not only more aggressive testing than VCT, but also other preconditions of successful testing scale-up, such as availability of affordable testing kits and competent health-care staff.⁴⁰

Some critics have noted that the low uptake of testing is not necessarily due to an inherent flaw of the VCT model, but that the barriers to increased uptake rather lie in the lack of government commitment to VCT, a lack of access to testing and little or no incentives to test.⁴¹ Heywood argues that "there has been a lack of investment in testing, the promotion of testing and in counselling" as well as the lack of incentives.⁴² The UNAIDS Global Reference Group on HIV/AIDS and Human Rights attributes the low coverage of HIV-testing to the low demand for HIV-testing. They attribute this low demand to the pervasive stigma that still attaches to the epidemic.⁴³ Human rights advocates in particular have called for better research and assessment of HIV-testing and in particular documenting and researching the "real life" experiences of people who test.⁴⁴

³⁹UN Integrated Regional Information Networks "Men falling through the cracks" July 25, 2005 Available: <http://www.aegis.com/news/irin/2005/IR050766.html>

⁴⁰ S Rennie & F Behets "Desperately seeking targets: the ethics of routine HIV testing in low-income countries" *Bulletin of the World Health Organization* January 2006, 84(1), 52-57: 52.

⁴¹ See Canadian HIV/AIDS Legal Network *et al* "Outcomes of the Symposium on HIV Testing and Human Rights" *op cit* and M Heywood "The Routine Offer of HIV Counselling and Testing: A Human Right" in HIV Testing In the Era of Treatment Scale Up, XVI International AIDS Conference, Toronto, Canada, 14 August 2006. Transcript available from http://www.kaisernetwork.org/health_cast/hcast_index.cfm?display=detail&hc=1830

⁴² Heywood *ibid*

⁴³ UNAIDS Global Reference Group on HIV/AIDS and Human Rights "Issue Paper: Current Debates on HIV Testing and Counseling" 2nd Meeting, 25-27 August 2003.

⁴⁴ The Symposium on HIV Testing and Human Rights for example called for an immense range of topics that necessitated research and monitoring. See Canadian HIV/AIDS Legal Network *et al op cit* p.5

While there may be debate on the effectiveness and impact of VCT and the underlying reasons for this, there is strong agreement from all sides that HIV-testing should be drastically expanded. It should be highlighted that very few commentators propose that the answer lies in mandatory testing,⁴⁵ which would violate the rights to privacy, autonomy and bodily integrity. One proposed model for increasing the number of people who are offered HIV-tests, is the “opt-out” approach which will be discussed below.

The “Opt-Out” approach to routine testing

A number of countries have started implementing testing models in addition to VCT. In Dallas, Texas, STI clinics have adopted an “opt-out” approach to testing since 1997. In September 2006, the CDC in the USA announced that it will be recommending “opt-out” testing for all patients in both public and private health care services. It defines “opt-out” screening as “performing HIV screening after notifying the patient that 1) the test will be performed and 2) the patient may elect to decline or defer testing. Assent is inferred unless the patient declines testing.”⁴⁶

Earlier this year, Tom Mastro from the CDC noted that the CDC was considering a move towards recommending “opt-out” testing because “HIV testing in the USA had not been increasing in recent years despite the fact that the CDC has launched its Advancing HIV Prevention strategy in 2003 to make voluntary HIV-testing a routine

⁴⁵ See for example the position of F. Venter who argues for mandatory HIV-testing in South Africa as articulated on “The After 8 Debate” SAFM, 24 October 2006.

⁴⁶ CDC “Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings” *MMWR Recommendations and Reports* September 22, 2006 / 55(RR14); 1-17, p.1. Available: <http://www.cdc.gov/MMWR/preview/mmwrhtml/rr5514a1.htm>

In particular, it recommends the following:

For patients in all health-care settings

- HIV screening is recommended for patients in all health-care settings after the patient is notified that testing will be performed unless the patient declines (opt-out screening).
- Persons at high risk for HIV infection should be screened for HIV at least annually.
- Separate written consent for HIV testing should not be required; general consent for medical care should be considered sufficient to encompass consent for HIV testing.
- Prevention counseling should not be required with HIV diagnostic testing or as part of HIV screening programs in health-care settings.

For pregnant women:

- HIV screening should be included in the routine panel of prenatal screening tests for all pregnant women.
- HIV screening is recommended after the patient is notified that testing will be performed unless the patient declines (opt-out screening).
- Separate written consent for HIV testing should not be required; general consent for medical care should be considered sufficient to encompass consent for HIV testing.
- Repeat screening in the third trimester is recommended in certain jurisdictions with elevated rates of HIV infection among pregnant women.

part of medical care”.⁴⁷ The Advancing Prevention Strategy included a routine offer of HIV-testing for patients at high- and low- HIV prevalence clinical settings, which did not require prevention counselling before the test.⁴⁸

Botswana health care services have been offering “opt-out” routine testing since 2004. It consists of a pre-test information session, the right to refuse the HIV-test and post-test counselling. Lesotho launched a “Know your status campaign” in March 2004. It consists of trained counsellors who will visit every household in the Lesotho and offer people HIV-testing, counselling and referral to post-test services.⁴⁹ The door-to-door offer of HIV-testing began in July 2006 in certain regions and is currently being rolled-out. While there is no report yet available from the Lesotho Department of Health, it was indicated that approximately 100 000 people have tested since the launch of the campaign. These statistics includes facility-based outreach testing as well as the door-to-door offer of an HIV-test.⁵⁰ Doctors working in Lesotho have expressed concern about the programme as there is currently a grave lack of medical personnel who can administer ARVs in Lesotho and insufficient support and infrastructure.⁵¹

In South Africa, the City of Cape Town has piloted a number of public health sector sites where routine testing is being offered. TB patients are routinely offered VCT, while a number of STI clinics are implementing an ACTS model, which denotes Assess, Consent, Test and Support.⁵² The ACTS model still offers HIV-testing to all people who attend the STI clinic and requires written consent from the patient, but there is a

⁴⁷ T Mastro “Normalising HIV Testing in healthcare settings” Symposium Presentation. Thirteenth Conference on Retroviruses and Opportunistic Infections, Denver, abstract 164, 2006. Quote taken from G. Cairns “New directions in HIV prevention: serosorting and universal testing” AIDSMAP News, 8 March 2006, Available:<http://www.aidsmap.com/en/news/506BAAD4-163A-422E-8D5F-B874E401A9C6.asp>

⁴⁸ CDC “Advancing HIV Prevention: New Strategies for a Changing Epidemic” *MMWR Weekly* April 18, 2003 / 52(15);329-332. Available: <http://www.cdc.gov/MMWR/preview/mmwrhtml/mm5215a1.htm>

⁴⁹ B Beresford “Lesotho gets tested” *Mail&Guardian* 6 June 2006 Available:

<http://www.mg.co.za/articlePage.aspx?articleid=276107&area=/insight/monitor/>

and L Maile, Director of the National HIV/AIDS Programme, Lesotho “Universal Access to HIV Testing and Counselling in Lesotho: The gateway to HIV prevention, treatment, care and support”, December 2005, Available: <http://www.who.int/hiv/capacity/1>

⁵⁰ Telephonic conversation between Marlise Richter and Ms Lebona, Coordinator: Know-your-Status campaign, Lesotho HIV/AIDS Directorate, 11 October 2006

⁵¹ Dr Pranitha Pillay, Medecins Sans Frontieres (Lesotho), Joint Civil Society Monitoring Forum 9th National Meeting, University of Cape Town School of Health, 5 October 2006.

⁵² Dr Pren Naidoo “The City of Cape Town and its model of scaling up VCT” Joint Civil Society Monitoring Forum 9th National Meeting, University of Cape Town School of Health, 5 October 2006. Available: <http://dedi20a.your-server.co.za/alp/images/upload/NaidooP.ppt>

modification to the amount of time spent on counselling. Data from the first quarter of 2006 shows a major increase in the number of people who test for HIV.

UNAIDS/WHO is in the process of drafting new recommendations on HIV-testing. The first draft of these recommendations entitled “Provider-initiated HIV Testing and Counselling in Clinical Settings: Operational Requirements” (‘Operational Recommendations’ or OR) was discussed with various international stakeholders at a meeting in July 2006.⁵³ At the time of writing, UNAIDS/WHO was reworking its draft and would invite comments on it after its finalisation.

What follows is a summary of the recommendations of the first draft of the Operational Recommendations (OR).⁵⁴ The OR model is discussed at length here as it sets out important terminology for HIV-testing, the rationale for Provider-initiated Testing and Counselling (PITC). If UNAIDS/WHO finalise the Recommendations, they will become very influential on how people are tested globally

The OR note that HIV-testing and counselling must be expanded by the expansion of client-initiated VCT, as well as HIV-testing services initiated by health care workers. The OR provide recommendations on the latter and are termed Provider-initiated Testing and Counselling. PITC consists of two main strategies:

Diagnostic testing

- It is part of the clinical process of all ill people.
- Is indicated when a person has symptoms which are suggestive of HIV/AIDS
- Is part of the regular diagnostic process.
- As with any medical consultation it involved confidentiality and the provision of information, on which the patient consents to treatment
- Patients must be provided with pre-test information and post-counselling
- Failure to provide HIV-testing when symptoms of HIV/AIDS are apparent, is deemed inadequate care and unacceptable

⁵³UNAIDS/WHO “Provider-Initiated HIV Testing and Counseling in Clinical Settings: Operational Recommendations”, Chavannes-de-Bogis, Switzerland, 3-4 July 2006.

⁵⁴ UNAIDS/WHO (2006) *op cit*

Routine Testing with the Right to Decline

- Patients attending health setting without obvious signs of HIV/AIDS, but will benefit from knowing their HIV status
- Includes people with STIs, those seen at antenatal clinics, TB clinics and drug treatment facilities. It will also include patients seen at in-patient and out-patient clinical facilities, depending on the resources available and HIV prevalence
- Health care workers will initiate HIV-testing and counselling as part of the package of services
- Patients will be informed of the HIV-test and their right to decline the test
- Patients will also be provided with pre-test information and counselling

The practical difference between the two main strategies may seem obscure to some observers. UNAIDS/WHO notes:

Although all HIV testing and counselling provides for the right to decline, it is emphasized in their second approach because the client may be accessing health services for another reason not linked to possible HIV infection. In diagnostic testing, the patient is presenting specifically to the clinic for a diagnosis and appropriate follow-up care and treatment which may be HIV related. The fact that the patient has come to the clinic seeking care indicates his or her willingness for the health care provider to make an accurate diagnosis.⁵⁵

The document is not entirely clear on how the 'difference in emphasis' in the right to refuse will be implemented, though that it is undeniably likely to have an all too tangible practical impact in the health care setting.

In this model, pre-test counselling is modified with the aim of providing basic information to obtain informed consent.⁵⁶ Counselling is done when the test results are relayed to the patient in the form of post-testing counselling. The model of informed consent that PITC utilises is an informed “right of refusal”. UNAIDS/WHO recommends that the health care worker should point out when offering the test, that the

⁵⁵ *ibid* p.6

⁵⁶ Pre-test information can be provided to individual or in group sessions and consists of:

- The clinical and prevention benefits of testing;
- A description of the testing and counseling process;
- Risks associated with HIV testing and disclosure
- The right to decline HIV testing and that testing will be performed unless they decline;
- The follow-up services that will be offered; and
- In the event of a positive test result, the importance of anticipating the need to inform anyone at ongoing risk who would otherwise not suspect that they were being exposed to HIV

patient's declining of a test would in no way affect his/her access to the health care services offered. If consent for HIV-testing is combined with consent to other procedures, the health care worker needs to specifically discuss with the patient the inclusion of the HIV-test. Consent is inferred unless the patient expressly declines the test, and written consent is not required.

Other salient points of the OR include:

- UNAIDS/WHO stress that the recommended model be adapted to each country's need, based on its available resources and epidemiology
- It does not recommend the diversion of resources away from other crucial programmes
- Anti-discrimination and stigma programmes are regarded as an essential part of the PITC approach
- A phased-in approach is recommended in circumstances where there are competing needs for funding
- PITC should become standard practice in clinical settings wherever it is likely to enhance the well-being and health of the individual
- PITC is recommended in settings even where ART is not available, but where other health benefits exist
- The minimum package of services that should be available for PITC is:
 - Basic care which includes treatment of common opportunistic infections and/or *cotrimoxale* prophylaxis
 - Basic prevention services which consists of condoms, PMTCT and HIV prevention counselling
- UNAIDS/WHO suggests various legal and policy frameworks that need to be included in the planning and design of the PITC activities
- Rapid tests are recommended for PITC
- "Task-shifting" will be required in most settings: Identifying appropriately skilled lay personnel who can receive training to carry out HIV-testing and counselling activities under the supervision of a trained health care worker with more specialised expertise

Critiques of Routine “Opt-Out” testing

Some human rights advocates have expressed strong reservations about the “Opt-Out” model. They warn that this model could slip into testing without consent and thus runs the danger of becoming mandatory testing.⁵⁷ Some advocates warn that if problems with human rights protections were reported with VCT, these problems would probably increase when routine testing models are introduced.⁵⁸ Heywood points out that in health care settings in Africa, “human rights principles of confidentiality and informed consent are still widely ignored”,⁵⁹ while the lack of counselling may have a negative impact on people’s ARV adherence if they seek and receive, treatment after diagnosis. Heywood argues that in many countries, despite clear policies and a commitment to VCT, counselling is still not implemented and that many people are tested without counselling or consent. In South Africa, a few studies have questioned the quality of counselling available and have noted client fears about discriminatory attitudes of health care workers, the lack of resources invested in counselling and payment of counsellors, as well as burn-out of counsellors.⁶⁰ The AIDS Law Project in South Africa has taken up a number of cases of PWAs whose rights were infringed upon by health care workers, as well as cases involving issues of HIV-testing and consent.⁶¹ Human rights conditions obviously differ from country to country. These conditions should inform the model to be adopted. The factors discussed above will have an adverse impact on HIV-testing and unless addressed, will be compounded with scale-up of testing.

Other concerns include whether the “opt-out” model could practically fulfil the requirements of consent, confidentiality and quality counselling.⁶² In particular, some human rights advocates are concerned about the nature of “informed” consent: whether

⁵⁷M. Heywood Toronto Conference (2006) *op cit* and the International HIV/AIDS Alliance “HIV testing and counselling: addressing the barriers to scaling up” Draft document 05/01/2006, p.10.

⁵⁸Canadian HIV/AIDS Legal Network *et al op cit* p.4 and P. Brouard “Opt out and voluntary HIV testing: where do we go from here?” Presentation to the Southern African HIV Clinicians’ Society, 26 October 2006, Rosebank, Johannesburg.

⁵⁹ M. Heywood “Human Rights and HIV/AIDS in the context of 3 by 5: time for new directions?” *Canadian HIV/AIDS Policy & Law Review* Vol. 9, No. 2, August 2004, 1,7-12: p.10.

⁶⁰ See for example L. Richter “Evaluation of HIV/AIDS Counselling in South Africa” Contract report submitted to the Department of Health, Nov 1999; A. van Dyk and P.J. van Dyk “What is the point of knowing?: Psychosocial barriers to HIV/AIDS Voluntary Counselling and Testing programmes in South Africa” *South African Journal of Psychology* 33(2), 2003, 118-125 and M. Chopra, D Jackson, A. Ashworth and T. Doherty “An Evaluation of the Quality of Counselling provided to Mothers in three PMTCT Pilot Sites in South Africa”, January 2004.

⁶¹ M. Richter ‘Aiding intolerance and fear: The nature and extent of AIDS discrimination in South Africa’ (2001) 5 *Law, Democracy & Development* 195-211 and AIDS Law Project Annual Reports.

⁶² Canadian HIV/AIDS Legal Network *et al op cit* p.3

patients would be able to raise sensitive questions during group pre-testing counselling sessions (which some “opt-in” models include), whether the skewed power relationship between health care worker and patient which could cause the patient to be intimidated into testing, as well as fears of the inadequate training or experience of health care workers.⁶³ One author points out that if informed consent no longer played a central role in health care services, there may not be much difference between health practice and veterinary practice.⁶⁴

Advocates are particularly concerned about the impact that a massive scale-up of testing would have in the absence of adequate support, treatment and care to meet the needs of a host of newly-tested PWAs.⁶⁵ Human rights groups expressed this point in the following way:

[I]mposing routine offer, particularly if testing is then done on an opt-out basis, in places where treatment, care and support and other prevention services are unavailable raises serious ethical and human rights questions. HIV testing is not done for its own sake. It is not always clear what services (if any) are available to a person who has tested HIV-positive.⁶⁶

The impact of routine testing on women has received particular attention. The links between gender based violence and HIV have been documented.⁶⁷ Many women fear violence when disclosing their HIV status to their partners or insisting on safer sex practices.⁶⁸ As the International HIV/AIDS Alliance rightly notes, “many women lack the autonomy to make decisions about HIV testing”, while “for many women, testing for HIV is dangerous”.⁶⁹ A number of women face the possibility of abandonment, violence and abuse from their partners if they reveal that they have gone for an HIV-test without their partner’s permission and/or have disclosed their HIV-positive status to their

⁶³ *ibid*

⁶⁴ Sofia Gruskin Expanding HIV Testing: Human Rights Issues" in HIV Testing In the Era of Treatment Scale Up, XVI International AIDS Conference, Toronto, Canada, 14 August 2006. Transcript available from http://www.kaisernetwork.org/health_cast/hcast_index.cfm?display=detail&hc=1830

⁶⁵ M. Heywood “A human rights based approach to scaling up VCT” Joint Civil Society Monitoring Forum 9th National Meeting, University of Cape Town School of Health, 5 October 2006.

⁶⁶ Canadian HIV/AIDS Legal Network *et al op cit* p.4

⁶⁷ Vetten, L. & Bhana, K. “Violence, Vengeance and Gender: A preliminary investigation into the links between violence against women and HIV/AIDS in South Africa”. Research report written for the Centre for the Study of Violence and Reconciliation, April. 2001.

⁶⁸ The Global Coalition on Women and AIDS and WHO “Violence against women and HIV/AIDS: Critical Intersections; Intimate Partner Violence and HIV/AIDS” International Bulletin Series, No. 1 Available:

<http://www.who.int/gender/violence/en/vawinformationbrief.pdf#search=%22links%20between%20gender%20based%20violence%20and%20HIV%22>

⁶⁹ International HIV/AIDS Alliance *op cit* p. 7 and 6.

partners. Some advocates express fears that women in particular would not be able to opt out of routine HIV-testing due to the uneven power relations in the health care setting between health care providers and patients.⁷⁰

At this point it is useful to note the findings of a symposium on disclosure and gender in Africa. This meeting brought together technical experts and researchers on policy and gender. It included the presentation of findings of research on women and disclosure globally, and studies in Kenya and Zambia specifically. The symposium concluded in the following way:

The data presented at the meeting demonstrate that the majority of HIV-positive women surveyed reported positive outcomes with disclosure of their HIV status, including less anxiety, fewer symptoms of depression, increased social support, and in many cases, a strengthening of the relationship with their partners. This finding suggests that the considerable scaling up of counselling and testing programs now underway may pose a lower risk of negative outcomes of disclosure for HIV positive women and suggest that there will be greater support for women than expected, even by women themselves.⁷¹

It is therefore important to bear in mind that while a number of women would run the risk of violence when disclosing, many may indeed be able to find unanticipated support from their partners.

Advocates point out that in countries with laws that criminalise HIV transmission, it would disproportionately affect women as they are more likely to know their HIV status than men with routine testing, and might not be able to negotiate safer sex with their partners despite the fact that they know they are HIV-positive. They may therefore face prosecution. The International AIDS Alliance insists that advocates of an “opt-out” model of testing address the following concerns specifically: “How do we support people who want to opt-out? If women want to opt-out because they fear violence, discrimination or other harms resulting from the results of their test, what can we do to support those women to test when it makes sense for them to do so?”⁷²

⁷⁰ Grace Sedio for example notes how difficult it is for women in Botswana culturally and socially, to refuse a person in power. G. Sedio "Expanding HIV Testing: The Point of View of Women Living With HIV" in HIV Testing In the Era of Treatment Scale Up, XVI International AIDS Conference, Toronto, Canada, 14 August 2006. Transcript available from http://www.kaisernetwork.org/health_cast/hcast_index.cfm?display=detail&hc=1830

⁷¹ USAID/Synergy *Women's Experiences with HIV Serodisclosure in Africa: Implications for VCT and PMTCT Meeting Report*. Washington DC: USAID, March 2004

⁷² International AIDS Alliance *op cit* p.8

Supporters of “opt-out” testing on the other hand, give a number of reasons why this form of testing is justified in circumstances where ART is available (some proponents such as UNAIDS/WHO make a case for “opt-out” testing even if there is only treatment of opportunistic infections available). Some of these benefits were discussed earlier under the section dealing with the normalisation of AIDS. It is argued that a de-emphasis on the strict requirements that are associated with VCT, will encourage more people to test, make the test more accessible and will make HIV/AIDS more like other chronic diseases and thus de-exceptionalise it.⁷³ A health care worker’s recommendation of an HIV-test may in fact assist the patient to overcome psychological blocks to finding out his/her status. Indeed a study in London on women’s attitudes towards “opt-in” as opposed to “opt-out” routine testing found that in the “opt-out” model pregnant women were less anxious about taking the test:

The uptake of the HIV test (88%) in this study [where the opt-out model was used] is more than double the rate (35%) achieved in the 1996-7 opt-in study. [...] This [opt-out] approach was not time consuming, required no extra staff, and was positively endorsed by most women. Compared with women in the opt-in study, the women were significantly less anxious and more knowledgeable about the protective effects of zivovudine [to prevent mother-to-child transmission]; there was no evidence that women found it difficult to decline a test.⁷⁴

If more people test, and more people know their HIV status, it will automatically decrease the levels of stigma in a society. Testing more people will help to channel PWAs who need ARVs into treatment programmes, and importantly, will assist a number of PWAs in starting treatment before they become ill. If the majority of cases of HIV transmission are attributable to people who are HIV-positive but do not know their status, a strategy that encourages (but never forces) more people to test will necessarily assist prevention efforts. Bayer and Fairchild in fact go so far as to argue that a model that makes it more difficult to say no to an HIV- test, may in fact be defensible on public health grounds: “Making it more difficult to say no may be justified by public health

⁷³ The UNAIDS Global Reference Group on HIV/AIDS and Human Rights states that “Advocates [of routine testing] argue that implementing routine testing, however defined, will enable a greater number of HIV infected individuals to know their status, be motivated to change their behaviours and prevent transmission, seek available care and support and treatment, if available, and plan for their futures and those of their family members” UNAIDS Global Reference Group on HIV/AIDS and Human Rights “Current Debates on HIV Testing and Counselling” Issue Paper, 2nd Meeting, 25-27 August 2003.

⁷⁴ WM Simpson, FD Johnstone, DJ Goldberg, SM Gormley and GJ Hart “Antenatal HIV testing: assessment of a routine voluntary approach” *British Medical Journal* Vol.318 19 June 1999, 1660-1661, p.1661. This study was conducted in London and cannot necessarily be extrapolated to the South African context. Yet, it indicates an important area of research in South Africa.

considerations, particularly by concern about preventable opportunistic infections in the persons who are unaware of their HIV infection and about transmission to their sexual or needle-sharing partners.⁷⁵ It is worth noting that the “opt-out” model has also been found to be cost-effective.⁷⁶

Botswana’s “opt-out” routine testing: Lessons for South Africa

Botswana’s HIV-testing policy has attracted a lot of attention. Botswana was the first country in Africa to implement a national ARV programme, which it launched in January 2002.⁷⁷ In 2004, the government decided to instigate an “opt-out” routine HIV-testing model, after its VCT programme did not attract a sufficient number of people to test, and thus ultimately to enrol in the ARV programme where appropriate. The Minister of Health in Botswana has lauded the programme as a success, indicating that since the change in policy, there has been a substantial increase in the number of people who test. She stressed the importance of training for health care workers.⁷⁸ Critics of the programme question whether there is empirical evidence that shows the programme succeeds on all levels. They have challenged the Department to provide data on the number of people who have been tested, who have declined testing, who are on treatment, how many adhere to their ARVs and to provide information on the budgets for training and counselling.

A number of human rights advocates working in Botswana have also expressed reservations about the testing programme. The Botswana Network on Ethics, Law and HIV/AIDS (BONELA) noted that there is not enough done to inform patients of their right to decline testing, that counselling is inadequate, and questions whether informed consent is being given.⁷⁹ It should be noted that many Botswana obey health care workers without question, which would impact on patient autonomy and decision-

⁷⁵ R. Bayer and AL Fairchild *op cit*

⁷⁶ G. Sanders *et al* “Cost-effectiveness of Screening for HIV in the Era of Highly Active Antiretroviral Therapy” *New England Journal of Medicine* February 10, 2005, 570-585.

⁷⁷ For a discussion of the evolution of HIV/AIDS policies in Botswana, see S. Heald “Abstain or Die: The Development of HIV/AIDS Policy in Botswana” *Journal of Biosocial Sciences* Cambridge University Press 2005, 1-13.

⁷⁸ Sheila Tlou “Routine Testing: The Botswana Experience – The Point of View of the Ministry of Health” HIV Testing In the Era of Treatment Scale Up, XVI International AIDS Conference, Toronto, Canada, 14 August 2006. Transcript available from http://www.kaisernetwork.org/health_cast/hcast_index.cfm?display=detail&hc=1830

⁷⁹ C Stegling “Routine Testing: The Botswana Experience – One Point of View” in HIV Testing In the Era of Treatment Scale Up, XVI International AIDS Conference, Toronto, Canada, 14 August 2006. Transcript available from http://www.kaisernetwork.org/health_cast/hcast_index.cfm?display=detail&hc=1830

making.⁸⁰ BONELA is concerned about the absence of an anti-discrimination framework in Botswana. Stegling, the director of BONELA, makes the following points:

The societal context is also characterised by stigma and discrimination in the context of HIV and AIDS. While HIV-related discrimination prevails, Botswana has, to this day, not enacted any legislation that protects the rights of people infected with HIV. For BONELA, running a legal aid clinic, it is a distressing reality to see on average two clients a day with complaints, such as unfair dismissal, refusal of employment and unfair treatment at the workplace due to a person's HIV positive status.⁸¹

It should also be noted that Botswana has an official policy of “shared confidentiality” in which a health care worker can disclose a patient's HIV status to the patient's caregivers without the patient's knowledge or consent.

A recent study assessed Botswana attitudes towards the testing policy 11 months after the introduction of the routine testing policy.⁸² The study found that 81% of the study participants were extremely or very much in favour of the policy. 48% of study participants self-reported that they had undergone an HIV-test, while 15% of people who had undergone HIV-testing reported having been tested by routine testing. Seemingly paradoxically, 98% reported either no ill treatment related to testing or regretted going for a test, but 68% of participants believed that they could not refuse the test even if they had initially decided to take the test by themselves. These findings are particularly puzzling not only because participants did not regard the fact that they could not refuse the test as ill-treatment, but also because most people seemed to have been tested through VCT, where theoretically the decision to test should be made in a less restrictive environment than with routine testing.

The study found that study participants with stigmatizing attitudes “had significantly lower odds of planning to get tested than those without stigmatizing attitudes”.⁸³ Equally worryingly, 43% of participants believed that routine testing would cause people to avoid

⁸⁰ IRIN News “Botswana: Routine HIV testing not as straightforward as it sounds” 1 February 2006, Available: http://www.irinnews.org/report.asp?ReportID=51474&SelectRegion=Southern_Africa&SelectCountry=BOTSWANA

⁸¹ Stegling (2006) *op cit*

⁸² Weiser SD, Heisler M, Leiter K, Percy-de Korte F, Tlou S, *et al.* “Routine HIV Testing in Botswana: A Population-Based Study on Attitudes, Practices, and Human Rights Concerns”. *PLoS Med* 3(7): e261, 2006. Available: <http://medicine.plosjournals.org/perlserv?request=get-document&doi=10.1371/journal.pmed.0030261>

The study was a cross-sectional, population-based study of 1 268 adults from 5 districts in Botswana.

⁸³ *Ibid* p.1018

seeking health care because of the fear of being tested. The authors note that “a majority of respondents felt that routine testing would decrease barriers to testing, HIV-related stigma, and violence towards women, and would increase uptake of ARVs through the Botswana National Treatment Programme”.⁸⁴ They conclude that the study’s findings “underscore the importance of implementing HIV-testing policies with measures in place to ensure informed consent, protection of confidentiality, and protection of women from gender-based violence related to testing”.⁸⁵

The Botswana experience is informative to South Africa, as it shows the importance of having a number of conditions in place for routine testing: treatment, confidentiality, consent and a protective legal environment for PWAs and women. It should also be borne in mind that South Africa differs from Botswana in a number of important respects: it has an extensive legal and policy framework that protects the rights of PWAs, ensures confidentiality of HIV status and it has numerous laws and policies in place which protect women from gender-based violence.

Home Testing

An area of HIV-testing that has not received sufficient attention and debate in South Africa is the greater availability of HIV home testing kits. In May 2005, the supermarket chain *Pick n Pay* explored the possibility of launching home testing kits for HIV at its outlets. The South African Medical Association (SAMA) reacted strongly against this possibility and called for “this commercial activity to be stopped immediately because it could be harmful to patients”.⁸⁶ The launch has subsequently been put on hold.⁸⁷ Yet, it is necessary to note that a number of pharmacies stock HIV home tests at a price that range from R40-R60 per test.⁸⁸

Arguments against home HIV-testing include fears about abuse of tests by employers or institutions in order to ascertain individuals’ HIV status; that the person who tests her HIV status herself, without the help and counselling of others, may inflict harm on herself; as well as concerns about the accuracy of the test and the window period.

⁸⁴ *ibid* p.1019

⁸⁵ *ibid*

⁸⁶ South African Medical Association Media Release “Doctors concerned about Home HIV/AIDS Test Kits” 24 May 2005.

⁸⁷ “Launch of HIV home testing kit delayed by outcry” Available: <http://www.ncf.org.za/docs/publications/consumerfair/vol3/launch.htm>

⁸⁸ Personal interviews with pharmacists at Mays Chemist, Melville, Johannesburg and Clicks Pharmacy, Campus Square, Melville, Johannesburg, 13 October 2005.

Yet proponents of the greater availability of HIV-testing kits, point out that some of these concerns could be addressed by appropriate regulation and guidelines. They argue that the greater availability of HIV home tests in pharmacies should be encouraged, in keeping with the emphasis on people taking greater responsibility for their own health and empowering themselves about medical issues that pertain to them. De Cock and Johnson point out that “While caution is clearly required, the reticence around the concept of self testing contrasts with modern approaches to self diagnosis or screening for other conditions such as breast self examination, home pregnancy testing, and melanoma awareness”.⁸⁹ Elsewhere, De Cock notes that more “work and reflection” are needed on home-testing and that “with much more experience with testing, one has to ask whether the negative attitudes towards self- and home-testing will not, in future, seem paternalistic and inappropriate”.⁹⁰ It is foreseeable that the greater availability of home tests will increase access to HIV-testing – especially for individuals who have fears about stigma and confidentiality when testing in public facilities, as well as to siphon off the burden of the “worried well” from the public and private health system.

It is clearly necessary that home testing should be more robustly debated in the South African context. In particular, the conditions under which home testing kits are currently available should be scrutinised and regulated. Recommendations on the regulation of home-test kits are as follows:

- Testing kits should be available as an over-the-counter diagnostic product in pharmacies only, while pharmacists should be encouraged to request the client to familiarise herself with the contents of the package insert, or indicate that it is beneficial to phone the helpline if the person is illiterate;
- Testing kits should clearly display the accuracy of the test;
- An information sheet in the testing kits should recommend that the user contact a toll free Helpline for counselling and assistance when taking the test. The diagnostic companies distributing the tests should set up agreements with specific helplines like the national AIDS helpline and LifeLine to train their counsellors in pre-and post-test

⁸⁹ De Cock and Johnson *op cit* p.291

⁹⁰ “D for diagnosis and E for everything else” Interview of Kevin De Cock with *the Bulletin of the World Health Organization*, October 2006, 84 (10) 774-775: 774. Available: <http://www.who.int/bulletin/volumes/84/10/interview1006/en/index.html>

counselling for people who conduct home tests and who require telephonic assistance;

- The information sheet should contain detailed information on HIV-testing with an emphasis on explaining the window period and the importance of confirming a positive HIV result at a clinic or hospital where appropriate management of HIV can be offered. The information booklet should be written in all 11 official languages;
- Clear warnings should be displayed on the pack that it is illegal to test other people for HIV.

Recommendations

This paper serves as an introduction to the different debates that are being conducted on HIV-testing. It is essential that the different strategies to increase HIV-testing are vigorously discussed and that the Department of Health in South Africa finalise its draft HIV-testing policy by consulting widely with civil society, clinicians and health care workers. A number of points are highlighted below to assist in the debate:

VCT

It is clear that more research is needed on the effectiveness and reach of VCT in South Africa. It is not recommended that VCT is entirely replaced by other models, but rather that new models complement and support VCT initiatives in South Africa. VCT should be strengthened, while different strategies to increase its reach should be considered, such as mobile clinics⁹¹ and providing incentives to test⁹².

Human Rights

In determining new models of testing for South Africa, it is vital that stakeholders stress the importance of training medical practitioners to be sensitive to clients' needs and context, and that no client is ever compelled to test for HIV. Counselling, consent and confidentiality should remain the mainstays of testing for HIV. Respecting and valuing human rights in HIV-testing - as with all aspects of the epidemic - are paramount, while advocates should guard against new models of testing becoming an implicit go-ahead for partner notification and mandatory testing.

⁹¹ See SF Morin et al "Removing Barriers to Knowing HIV Status – Same-day Mobile HIV Testing in Zimbabwe" *J Acquir Immune Defic Syndr* Vol. 41, No. 2, 1 February 2006, 218-224

⁹² R Thornton "The demand for and impact of learning HIV status: Evidence from a field experiment" Harvard University, 11 November 2005. Available: <http://www.sarpn.org.za/documents/d0001905/index.php>

The legal framework for protecting the rights of PWAs in South Africa should be supported and strengthened. Proposed changes to the “Promotion of Equality and Prevention of Discrimination Act” to include the explicit prohibition of discrimination on grounds of “HIV/AIDS status” should be strongly supported.⁹³ Increasing and supporting access to justice for PWAs is vital.⁹⁴ Proposed changes to the Sexual Offences Bill to criminalise negligent HIV-behaviour might discourage people from knowing their status in case it may lead prosecution, and should therefore be resisted.⁹⁵

Training

On-going training of counsellors and health care workers on how to approach HIV-testing is a vital component in addressing human rights concerns with regards to HIV-testing. Indeed a new testing model should require a strong emphasis on (re)training of medical practitioners, and in particular “training on HIV testing and counselling [that] should stress the patient’s right to decide whether or not to be tested”⁹⁶ Rennie and Behets call attention to the following: “In their interaction with patients, health-care professionals must delicately balance the public health and clinical benefits of testing with the individual’s right to refuse testing”.⁹⁷ It is vital that medical practitioners constantly remind themselves of the unequal power relationship between themselves and their patients,⁹⁸ how the discrepancy in power may impact on the patient’s fears⁹⁹ and the decision-making process. They should attempt to ameliorate these effects by reassuring the patient that there will not be any adverse effects to the relationship if the patient

⁹³ See AIDS Law Project “Submission on the Promotion of Equality and Prevention of Unfair Discrimination Act, 2000” Joint Monitoring Committee on the Improvement and the Quality of Life and the Status of Women and Joint Monitoring Committee on the Improvement and the Quality of Life and the Status of Children, Young and Persons with Disabilities, 22 September 2006. Available: www.alp.org.za

⁹⁴ See “Consensus Statement on Improving Access to Legal Services for People living with HIV/AIDS”. From the conference on HIV and Access to Legal Services, held at Wits University, 17-18 February 2006. Available:

<http://www.alp.org.za/modules.php?op=modload&name=News&file=article&sid=280>

⁹⁵ AIDS Law Project submission on the Sexual Offences Bill, 15 August 2006, Available:

<http://dedi20a.your-server.co.za/alp/images/upload/SexOffBill.15.8.06.doc>

⁹⁶ UNAIDS and WHO “Report: Consultative Meeting on HIV Testing and Counselling in the Africa region” *op cit* p.7.

⁹⁷ Rennie and Behets *op cit* p.54

⁹⁸ The uneven power relationship is shaped by a myriad of interlocking factors including race, gender, class, employment and level of education

⁹⁹ Rennie and Behets write the following: “Patients may not opt-out of testing because they believe that their doctor will react negatively to their refusal and/or fear they will receive inferior care as the result of their ‘incorrect’ decision” Rennie and Behets *op cit* p.54

refuses the HIV-test. This training should be focused on what Heywood describes as “counseling that is sensitive to human rights and ethics in the practice of medicine”.¹⁰⁰

The recommendations on “task-shifting” by UNAIDS/WHO are supported here. UNAIDS/WHO suggests that appropriately skilled lay personnel be identified who can receive training to carry out HIV-testing and counselling activities under the supervision of a trained health care worker with more specialised skills. This will alleviate at least some of the burden on health care workers and clinicians in dealing with the epidemic.

Gender

The adverse effects that HIV-testing may have on women should particularly be borne in mind when considering HIV-testing models in South Africa. Medical practitioners need to be mindful of women’s relative lack of power in relationships and in society in general and ensure that no undue pressure to test is exerted. Health care workers should be particularly attentive to gender based violence and assist women with referrals, as well as to support any decisions they make regarding HIV-testing.

Conclusion

The testing debate holds particular dilemmas for human rights advocates in the AIDS field. It is clear that they risk being sidelined if the approach they adopt is inappropriately rigid or unresponsive to new strategic landscape. While preliminary research has indicated that there has been an increase in the uptake of VCT services with the availability of ARVs, this increase is not dramatic enough to ensure that all South Africans who need to test for HIV will volunteer do so in the near future. The rising tide of AIDS-related deaths in South Africa, the availability of ARVs (albeit still limited) and South Africa’s solid legal and policy framework for protecting the rights of PWAs are pressing reasons for an urgent revision of HIV-testing strategies in South Africa. It is vital that new testing models and strategies increase the number of people who know their HIV status, which will expand the collective knowledge of managing HIV, strengthen prevention programmes and make some progress towards the “de-exceptionalisation” of the epidemic. It is anticipated that these factors will progressively decrease the levels of AIDS stigma in society – a critical component for effectively

¹⁰⁰ MJ Heywood “The Routine Offer of HIV Counseling and Testing: A Human Right” *Health and Human Rights*, Vol.8, No.2, 13-19: 17.

engaging with the epidemic, and mitigating its effects. In order to increase the number of people testing for HIV, it is vital that possible barriers to testing are minimised to encourage people to test, while simultaneously retaining the all-important human rights protections of PWAs

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Appendix A

HIV-testing data from 6 provinces

Province	Kwa-Zulu Natal	Limpopo	Eastern Cape	Western Cape	Free State	Mpumalanga
Does your province keep records of VCT utilisation?	Yes	Yes	Yes	Yes	Yes	Yes
People tested in 2004 (VCT)	525 126 (2004 & 2005)	70 522	117 510 (151 949 counselled)	216 577		38 100
People tested in 2005 (VCT)	525 126 (2004 & 2005)	113 077	147 450 (212 730 counselled)	154 963 (Jan-Sept 05)	71 165 (March 05 – Feb 06)	64 659
People tested in 2004 (PMTCT)	512 224 (time period unclear)	38 114	38 580 (2004/05)	80 824	20 001	12 675 (2004/05)
People tested in 2005 (PMTCT)		59 152	52 732 (2005/06)	83 86	23 760	27 002 (2005/06)
People tested in 2004 (PEP)	Information unclear	Not avail	3700 (April '04 - Mar 05)	3713		428 (2004/05)
People tested in 2005 (PEP)	Information unclear	Not avail	3700 (April '04 - Mar 05)	3462	2380 (2005-2006)	367 (2005/06)
Were the partners of women who come for PMTCT also offered an HIV-test?	Partners are offered a test	No	Offered	No, as 90% of cases the partners do not accompany the women	Info not collected	No

Provincial budget for HIV-testing	Current; R11 440 000 (includes R5 040 000 for PMTCT programme)	R22 998 000 (Testing kits: R 2540 000 Marketing of VCT: R106 000)	R26 489	R18 000 000	R9 132 000 (2006/07)	Whole budget not available 2006/2007 for HIV rapid tests: R 2 020 000 2006/2007 ELISA and PCR laboratory testing: R8 150 000
Records of VCT kept?	Yes	Yes	Yes	Yes	Yes	Yes
Is there a Monitoring system for HIV-testing in place?	Yes	Yes	Yes	Yes	Yes	Yes