

# SCALING UP HIV TESTING IN RESOURCE-CONSTRAINED SETTINGS: DEBATES ON THE ROLE OF VCT AND ROUTINE 'OPT-IN OR OPT-OUT' HIV TESTING

**Ann Strode**, Faculty of Law, University of KwaZulu-Natal

**Heidi van Rooyen**, Human Sciences Research Council

**Mark Heywood**, AIDS Law Project, University of the Witwatersrand

**Quarraisha Abdool Karim**, CAPRISA, University of KwaZulu-Natal, and Department of Epidemiology, Columbia University, New York

Scaling up of the numbers of people voluntarily undergoing HIV testing has become vital, especially in resource-constrained settings, where the need for knowledge of HIV status for both prevention and care is critical. The reality is that for most people in Africa, access to HIV testing and to voluntary counselling and testing (VCT) has been very limited, and this has human rights implications – missing the opportunity to be diagnosed with a disease that is now well understood, manageable and treatable means certain death.

The key challenge in our current context is how scaling up of HIV testing should be done. In responding to this challenge, we are guided by Gruskin and Loff,<sup>1</sup> who state that 'A human rights approach mandates that any public strategy, whether or not rights are to be restricted, be informed by evidence and widely debated. This approach protects against unproved and potentially counterproductive strategies, even those motivated by the genuine despair in the face of overwhelming public health challenges.'

This article describes the arguments and discussion raised during a session on models for increasing access to HIV testing at the 2nd National Conference on HIV/AIDS held in Durban in June 2005. It describes the legal framework for HIV testing in South Africa, frames the issues at the heart of the debate, and describes and discusses the various models of HIV testing, routine HIV testing, VCT and mandatory or compulsory HIV testing, within the context of HIV prevention and care. It concludes with recommendations.

## THE LEGAL FRAMEWORK FOR HIV TESTING

The Constitution provides that every person has the right to bodily integrity and privacy (s 12 and s 14, Constitution of the Republic of South Africa Act, No. 108 of 1996). These rights give individuals control over their bodies and enable them to make autonomous decisions (De Waal *et al.*,<sup>2</sup> p. 262). These rights are also well-established principles in our common law.<sup>3</sup> More recently the National Health Act (No. 61 of 2003) has codified these rights, stating that no health service may be provided to a user without their consent (s 7, National Health Act).

In other words, patients must give their consent to medical treatment including HIV testing (Dada and McQuoid Mason,<sup>4</sup> p. 8). Accordingly, they may also refuse to be treated or undergo a diagnostic test.<sup>5</sup> The requirements for valid consent include: the patient must have knowledge of the nature and extent of the harm or risk involved, appreciate and understand

the nature of the harm or risk and consent to the harm or assume the risk.<sup>6</sup>

Rights are not absolute, and the Constitution provides that they may be limited if this is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom (s 36, Constitution of the Republic of South Africa Act). The Constitutional Court has held that this requires a proportionality analysis which examines the purpose, effects and importance of the legislation and the nature and the extent of the limitation of rights. The more substantial the inroad into individual rights the more compelling the ground for justification must be (Currie *et al.*,<sup>7</sup> p. 341).

## FRAMING THE DEBATE

De Cock and colleagues, who kicked off the routine testing debate in their 2002 article in the *Lancet*,<sup>8</sup> framed the issue as public health v. human rights. Given the increasing availability of ARVs, an 'exceptionalist' insistence relying primarily on

informed consent, sometimes described as a Western medical importation, has been the main deterrent to the uptake of HIV testing. Accordingly, De Cock *et al.* state that: 'Routine testing should not require consent or pre-test counselling provided that all clients are informed that routine testing is part of the package of services for which they are voluntarily attending' (p. 70).

When framed in this manner the debate centres around whether a human rights-based approach to HIV is impeding our public health response to the epidemic. This assumes that the debate is whether a public health or a human rights-based approach is more effective. We argue that this is an artificial polarisation that detracts from the key issues. This debate centres on the slow uptake of HIV testing in resource-constrained settings, and it should be framed around a problem analysis based on the following questions:

- Why is the uptake of HIV testing slow? Is uptake influenced by the nature of current models for HIV testing?
- What is the legal framework and how does it influence policy decisions regarding models for HIV testing?
- What are the gender implications of the various models of HIV testing?
- Could adopting new models for HIV testing influence uptake of HIV testing and access to ARVs?

## MODELS FOR HIV TESTING

There are currently three models for HIV testing in a South African context. They are not mutually exclusive and could all play different roles within a broader public health strategy to combat HIV/AIDS.

### ROUTINE HIV TESTING

There are many forms of routine HIV testing currently being discussed and implemented in a somewhat *ad hoc* manner. However, it appears that a routine offer of HIV testing during any encounter with the health care services, with the option of 'opting in' or 'opting out' of testing, is increasingly being implemented.

#### Does the law allow routine HIV testing?

There is no legal obstacle to the state introducing a policy of routine HIV testing provided that the testing process continues to meet the requirements for lawful informed consent. A key issue would be whether a routine offer of HIV testing with the option of opting in or out of testing enables patients to act voluntarily. Consent may not be induced by fear, force, threats, duress, coercion, compulsion, deceit, fraud, undue influence, perverse incentive or financial gain (Van Oosten,<sup>9</sup> p. 29). In this regard, careful consideration must be given to gender issues, power imbalances and other subtle factors that may affect patient autonomy.

#### Arguments for routine HIV testing

There are several reasons why it could be argued that routine

testing is merited. Firstly, the unprecedented scale of the HIV epidemic and the generalisation of vulnerability to HIV infection necessitates more traditional health measures to capture those who are vulnerable – but do not view themselves as at risk. Secondly, the advent of treatment and the fact that HIV testing is a 'gateway' to access to treatment necessitates this move. And lastly, there is the reality that in most high-prevalence and resource-constrained countries, ARV treatment only reaches a fraction of those who qualify for it. According to clinical guidelines reaching vulnerable populations remains a major imperative for the scale-up of testing. Routine testing will 'enable a greater number of HIV infected individuals to know their status, be motivated to change their behaviour and prevent transmission, and seek available care, support and treatment...'<sup>10</sup>

#### Arguments against routine HIV testing

*De facto* routine testing of only certain populations can lead to new stigma against those populations. For example, the implementation of routine testing among populations at risk who are either captive (such as prisoners) or depend on access to health care services because of their gender (such as pregnant women) could, instead of destigmatisation of HIV through its de-exceptionalisation, do the opposite.

Routine testing is open to the possibility of abuse of patients – there is the possibility that if no clear guidelines and procedures are put in place, patients may be coerced into taking an HIV test without full knowledge of the procedure and its impact. In practice, it may be difficult for patients to refuse testing at any stage of the process. For example, in Botswana organisations like the Botswana Network on Ethics Law and HIV (Bonela) argue that the 'opt-out' policy has evolved into a policy of routine testing with minimal counselling and subtle coercive pressures to deter people from opting out. Although the policy might be reaping short-term benefits by identifying people in need of treatment, its longer-term consequences are likely to be poor adherence to treatment as well as continued misunderstandings about HIV.

Many developing countries do not yet have the means effectively to apply new strategies like routine or opt-out testing, in which health care workers make a point of offering (and providing) more HIV tests.

Taking the 'V' and 'C' out of VCT limits the prevention and risk reduction outcomes that are critical within HIV and AIDS. Furthermore, there is little empirical evidence to support the belief that removing the voluntary informed consent and counselling components of VCT will lead to greater uptake of ARVs in developing contexts.

Gender is an important dimension of the HIV pandemic.<sup>11,12</sup> The stark social, economic and political power imbalances between men and women are a major factor influencing HIV risk.<sup>13,14</sup> Policies promoting routine testing may fail to recognise the supportive role of counselling. This could undermine important gains made in prevention of mother-to-child transmission (PMTCT) programmes.

## VOLUNTARY COUNSELLING AND TESTING

VCT is a combination of two activities, counselling and testing, into a service that amplifies both. The objectives of VCT are the prevention of HIV transmission and the provision of emotional support of those who wish to consider HIV testing – to help the person make a decision about whether or not to be tested, and to provide support and facilitate decision making following testing.

### Does the law require VCT before HIV testing?

The law does not specifically state that patients should undergo VCT before HIV testing. However, the counselling process involved in this model of HIV testing does ensure that the key elements of lawful informed consent are met, namely the provision of information, understanding, appreciation and unequivocal agreement to be tested.

### Arguments for VCT

The rationale for HIV counselling and testing as a pivotal response in the HIV/AIDS pandemic is well established. HIV/AIDS is primarily a social phenomenon arising from a compelling disease<sup>15</sup> that gives rise to a range of behavioural, psychological and social consequences for both those infected with and those affected by the HIV.

VCT provides a significant prevention opportunity for dissemination of accurate information about HIV/AIDS, for risk assessment and risk reduction counselling (regardless of serostatus), for counselling about options to reduce HIV (MTCT), and for information and referral to medical services specific to treatment of such associated infections as sexually transmitted diseases or such opportunistic infections as tuberculosis.

VCT has been shown to be a demonstrably effective secondary prevention strategy that assists HIV-positive individuals and serodiscordant couples reduce the risk of infecting others or of re-infecting themselves.<sup>16-19</sup> Its role as a primary prevention strategy for HIV-negative people as well as the long-term effects of VCT are less clear.<sup>16,17</sup> Despite these apparent limitations of VCT, a recent comprehensive review concluded that most VCT studies reveal significant benefits to persons following VCT.<sup>19</sup>

With regard to the supportive goal of VCT, there is growing research evidence to suggest that VCT plays an important role in assisting people to cope with a range of psychosocial sequelae associated with an HIV-positive diagnosis.<sup>19,20-23</sup> There is therefore demonstrable research evidence that VCT works on both prevention and support levels. For example, a recently completed study highlights the fact that good counselling is integral to PMTCT implementation and effectiveness.<sup>24,25</sup> The study showed that supportive counselling was vital in helping women manage potentially negative reactions of spouses or family members, but also in encouraging partner support, co-counselling and HIV testing. Further, knowledge of HIV status and counselling was a major means of empowering women to enforce their individual

choices surrounding, for example, infant feeding and protected sexual intercourse.

The lack of utilisation of VCT is due to its limited availability. This reflects the starving of health care services of financial and human resources and the reticence of governments to deal with the HIV/AIDS epidemic properly from a health perspective. Other reasons for the slow uptake of VCT could be widespread fear of taking the test; concerns that confidentiality will be breached; stigma and discrimination; and the costs associated with the service.

### Arguments against VCT

Many argue that where VCT was once the first point of service to a range of services that people might need, it now acts as a bottleneck to enabling rapidly increased access to treatment.<sup>10</sup> There is a growing perception that it is the 'V' and 'C' in VCT that creates this bottleneck.

## MANDATORY OR COMPULSORY HIV TESTING

Mandatory or compulsory HIV testing occurs when laws limit the rights of individuals to bodily integrity by requiring HIV testing. Failure to comply could have legal implications.

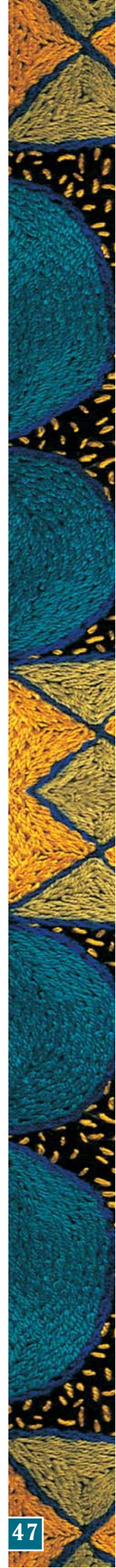
### Does the law allow mandatory HIV testing?

There is no legislation (as yet) that specifically provides for mandatory HIV testing in South Africa. However there are two areas in which legislation could be developed:

- The National Health Act (No. 61 of 2003) allows the Minister of Health to issue regulations regarding communicable diseases (s 90(1)(j), National Health Act). In terms of similar powers provided in the previous Health Act (No. 63 of 1977) the apartheid government in 1987 issued the Regulations relating to Communicable Diseases and the Notification of Notifiable Medical Conditions (Government Notice R 2438 in *Government Gazette* 11014 of 30 October 1987). These regulations allowed for mandatory medical examinations (which could include HIV testing) in a number of circumstances. They were widely criticised<sup>26</sup> and were apparently never implemented.<sup>27</sup> To date no regulations have been issued in terms of the new National Health Act.
- In our criminal law there are currently no provisions for mandatory HIV testing. However the South African Law Reform Commission has in its *Fourth Interim Report on Aspects of the Law Relating to AIDS*<sup>27</sup> recommended that parliament adopt its proposed Compulsory Testing of Sexual Offenders Bill which would allow the victim of any sexual offence to apply to a magistrate for an order compelling the alleged offender to be tested for HIV.

### Arguments for mandatory testing

It is argued that mandatory testing promotes public health goals and the public good. Mass testing programmes could enable the early identification and treatment of large numbers of persons, thus reducing the number of new infections.<sup>28</sup> It is also seen to be a justifiable infringement of an individual's right to bodily integrity and privacy (in certain circumstances)



as the benefits to the individual and society outweigh the individual cost.<sup>29</sup> Finally, it enables HIV treatment to be provided to vulnerable and marginalised groups.

### Arguments against mandatory testing

Protecting the human rights of persons infected and affected by HIV serves to promote public health goals rather than undermine them. Where persons are at risk of HIV infection they need to be able to access public health services. Where persons are coercively tested or may face stigma and discrimination following testing they are unlikely to access such services and are often driven underground.<sup>29</sup> Furthermore, infringing rights such as the rights to privacy, dignity and bodily integrity is not justifiable<sup>30</sup> and compulsory testing frequently results in increased vulnerability for such groups.<sup>31</sup> For example, compulsory testing of sex workers who use health care services may simply further stigmatise this group and act as a barrier to their accessing health services.

## CONCLUSION

In this rapidly changing context of an evolving epidemic and new interventions to reduce HIV transmission and alter the natural history of infection, we need to critically examine the problems with current approaches and look at how we can improve a range of interventions.

VCT depends on the voluntary entrance of at-risk groups to the health service. In the absence of public health strategies that loudly encourage VCT among the population generally, it is bound to have limited impact. However, its real benefit has been for the small numbers of people who chose and then were able to access the service. Routine testing, on the other hand, is presenting itself as a new public health strategy, a necessary measure to allow health care services to identify much greater numbers of those who are already infected.

Increasing access to treatment is a critical intervention in the epidemic, but should not be at the expense of preventing further transmission of the virus. We need both. Public health and human rights can have common goals. Thus, we argue that this debate should centre on how to ensure more V, more C and more T – to leave any part out of the equation either has human rights or public health implications. Testing without voluntarism is most definitely a human rights and a public health violation. Testing without counselling will not have the beneficial impact on either prevention or treatment that it seeks; for routine testing to succeed as either a prevention or treatment strategy, it will still depend upon the quality of counselling that accompanies it.

Finally, in conclusion we submit that there is some synergy between the models for HIV testing. A routine offer of HIV testing could be used to promote access to VCT. Accordingly we argue that a routine offer of HIV testing should be made to those considered at risk for HIV, e.g. those attending sexually transmitted infection clinics, pregnant women, and those presenting to health services with signs and symptoms

of advancing HIV disease including tuberculosis. The routine offer of HIV testing in public health facilities should continue to create opportunities for patients to make an informed, confidential decision to test or not. Clients should be encouraged to disclose their HIV status and to encourage others in their lives to test too. A routine offer of HIV testing should not undermine VCT but rather promote access to it.

Further, we recommend that in making public health policy decisions on models for HIV testing we should be:

- Cognisant of the context.
- Not compromise many gains we have made over the years with regard to human rights.
- Foster evidence-based decision-making which requires the establishment of the relationship between HIV testing and prevention outcomes; determines the relationships between VCT and ARV uptake and HIV testing and ARV uptake; and identifies whether the 'V' and the 'C' are really causing the bottleneck to testing.
- Ensure that HIV testing is expanded to those who are asymptomatic.
- Understand and address the reasons for the low uptake of VCT in developing contexts.
- Based on a thorough gender analysis.
- Compare the different models of HIV testing being provided to establish uptake through each, and understand better the decision-making process in each setting, the role of different levels of coercion or voluntariness on decisions to test, and the consequences thereof.

### REFERENCES

1. Gruskin S, Loff L. Do human rights have a role in public health work? *Lancet* 2002; **360**: 1880.
2. De Waal J, Currie I, Erasmus G. *The Bill of Rights Handbook*. 4th ed. Cape Town: Juta, 2001: 246-264.
3. *Stoffberg v Elliot* 1922 CPD 148, p. 148.
4. Legal aspects of medical practice. In: Dada M, McQuoid Mason DJ, eds. *Introduction to Medico-Legal Practice*. Durban: Butterworths, 2002: 3-32.
5. *C v Minister of Correctional Services* 1996 (4) SA 292 (TPD), 301 B.
6. *Lambert v Hefer*, No. 1955 (2) SA 507 at 507 G-H.
7. Currie I, De Waal J, de Vos P, Govender K, Klug H. The structure of the Bill of Rights. In: *The New Constitutional and Administrative Law*. Cape Town: Juta, 200: 317-344.
8. DeCock KM, Mbori-Ngacha D, Marum E. Shadow on the continent: public health and HIV/AIDS in Africa in the 21st Century. *Lancet* 2002; **360**: 67-72.
9. Van Oosten F. The law and ethics of information and consent in medical research. *Tydskrif vir Hedendaagse Romeins-Hollandse Reg* 2000; **63**: 29.
10. UNAIDS Global Reference Group on HIV/AIDS and Human Rights. *Issue Paper: Current Debates on HIV testing and Counselling*. Geneva: UNAIDS, 2003: 2.
11. Tallis v. AIDS a crisis for women. *Agenda* 1998; No. 39, 6-14.
12. Abdoal Karim Q. Women and AIDS – the imperative for a gendered prognosis and prevention policy. *Agenda* 1998; No. 39, 15 - 25.
13. Weiss E, Gupta RG. *Bridging the Gap: Addressing Gender and Sexuality in HIV Prevention. Findings From the Women and AIDS Research Program*. International Centre for Research on Women, 1998.
14. Wingood GM, DiClemente RJ. Application of the theory of gender and power to examine HIV-related exposures, risk factors, and effective interventions for women. *Health Educ Behav* 2000; **27**(5): 539-565.
15. Richter L, van Rooyen H, Solomon V, Griesel R, Durrheim K. Putting HIV/AIDS counselling in its place. *Society in Transition*, 2001; **32** (1): 148-153.
16. Wolitski R.J, MacGowan R.J, Higgins DL, Jorgensen CM. The effects of HIV counselling and testing on risk-related practices and help-seeking behaviour. *AIDS Educ Prev* 1997; **9**: 52-67.
17. Weinhardt L, Carey M, Johnson B, Bickham N. Effects of HIV counselling and testing on sexual risk behaviour: A meta-analytic review of published research, 1985-1997. *Am J Public Health* 1999; **89**: 1397-1405.
18. Voluntary HIV-1 Counselling and Testing Efficacy Study Group. Efficacy of voluntary HIV-1 counselling and testing in individuals and couples in Kenya, Tanzania and Trinidad: A randomised trial. *Lancet* 2000; **356**: 103-112.

19. UNAIDS. *The Impact of Voluntary Counselling and Testing: A Global Review of the Benefits and Challenges*. Geneva: UNAIDS, 2001.
20. Lie G, Biswalo P. Perception of appropriate HIV/AIDS counsellors in Arusha and Kilimanjaro regions of Tanzania: Implications for hospital counselling. *AIDS Care* 1994; **6** (2): 139-151.
21. Lie GT, Biswalo PM. HIV-positive patients choice of a significant other to be informed about the HIV test result: findings from an HIV/AIDS counselling programme in the regional hospitals of Arusha and Kilimanjaro, Tanzania. *AIDS Care* 1996; **8**: 285-296.
22. Baggeley R. Fear of knowing: why 9 in 10 couples refused HIV tests in Lusaka, Zambia. *Abstract No. E.1266*. 10th International Conference on AIDS and STDs in Africa, Abidjan, 7-11 December 1997.
23. Kraabendum AA, Kuijper B, Wolffers IN, Drew R. The impact of counselling on HIV-infected women in Zimbabwe. *AIDS Care* 1998; **10** (1): S25-S37.
24. Chopra M, Jackson D, Ashworth A, Doherty T. An evaluation of the quality of counselling provided to mothers in three PMTCT pilot sites in South Africa. World Health Organisation, January 2004.
25. Perez P, Orne-Gliemann J, Mukotekwa T, *et al*. Prevention of mother to child transmission of HIV: evaluation of a pilot programme in a district hospital in rural Zimbabwe. *BMJ* 2004; **329**: 1147-1150.
26. Cameron E, Swanson E. Public health and human rights – the AIDS crisis in South Africa. *South African Journal of Human Rights* 1992; **8**: 200-233 (at p. 213).
27. South African Law Reform Commission. *Fourth Interim Report on Aspects of the Law relating to AIDS: Compulsory Testing of Sexual Offenders*. Pretoria: South African Law Reform Commission, 2001.
28. Holbrooke R, Furman R. A global battle's missing weapon. *New York Times* 2004; 10 February.
29. South African Law Reform Commission. *Second Interim Report on Aspects of the Law Relating to AIDS: Pre-Employment HIV Testing*. Pretoria: South African Law Reform Commission, 1998.
30. Women's Legal Centre. *Submission in Response to Draft Regulation No. R 485 Relating to AIDS Notification as Contained Within Government Gazette Dated 23rd April 1999*. Cape Town: Women's Legal Centre, 1999.
31. Heywood M. *The Implications of 'AIDS Notification' for Human Rights and HIV/AIDS Prevention in South Africa*. Johannesburg: AIDS Law Project, 1999.

