

# THE ROUTINE OFFER OF HIV COUNSELING AND TESTING: A Human Right

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**F**or over a decade, the duty to obtain informed consent for HIV testing was one of the most inviolable precepts of the human rights approach to the HIV epidemic. In the course of 2004, however, a charge toward a “new approach” to HIV testing gathered pace and supporters.

The year began with Botswana President Festus Mogae implementing a new policy of routine HIV testing under which, henceforward, all people in Botswana would automatically be offered an HIV test when they utilized health services.<sup>1</sup> Those who did not want an HIV test would have the right to “opt-out.” Although the offer of an HIV test does not in and of itself violate the established principles of informed consent, it does shift the onus of requesting the test from the patient to the provider. This might appear an innocent shift, but in countries where the relationship between health users and providers is an unequal one, it is likely to be interpreted as a request to test rather than an offer.

Later in the year, both UNAIDS and WHO, partly in response to Botswana’s initiative, endorsed the “routine offer” of an HIV test and advocated mainstreaming HIV testing into health care services in countries with a high HIV prevalence.<sup>2</sup> However, both organizations were careful to warn against the new approach being a cause of human rights violations and were careful to situate it within the human right to HIV prevention and treatment services.<sup>3</sup> They also

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differed with Mogae's "opt out" policy, by placing greater emphasis on the offer of the HIV test and accompanying pre-test counseling.

The year 2004 ended with a UNAIDS/WHO Consultation on Testing and Counseling, which dropped the customary V (as in *voluntary* testing and counseling) and invented a new acronym, T & C, to stand for testing and counseling. The consultation endorsed the need for a scale up of HIV testing but nonetheless identified a range of risks, including "high demand for testing leading to inability to provide treatment to those eligible for treatment." Significantly, it stopped short of making new recommendations, although it endorsed the "3 Cs (confidentiality, counseling, and informed consent) for all HIV testing."<sup>4</sup> The question now, therefore, is whether the testing policy debate has traversed a circle and ended up reaffirming the "traditional" approach to VCT, or whether the era of routine testing (implicitly less voluntary, less confidential, and with consent as opposed to informed consent) has in fact commenced.

### **Is the Routine Offer of Testing a Right?**

The issue is relatively straightforward.

Giving millions more people access to an HIV test and the services integral to it has become a necessity in the face of:

- the explosion of the AIDS epidemic in many developing countries,
- the growing burden of largely preventable HIV-related mortality and morbidity, and
- WHO's important 3 by 5 Initiative to support national programs with the aim of enrolling at least 3 million people on anti-retroviral (ARV) treatment globally by the end of 2005 and the declared objective of working towards universal access to ARVs.

A commitment to the routine offer of testing has also become necessary because in most developing countries easy access to counseling, an HIV test, and information about AIDS in health facilities has been as scarce as access to anti-retroviral drugs. Judging by the UNAIDS International

Guidelines on HIV/AIDS and Human Rights, however, it should be as much of a human right.<sup>5</sup>

A survey of the debate that has been generated about routine testing seems to suggest that the discussion has coalesced into two broad schools of thought with diehard RCT-ers (routine counseling and testing) at one end of the spectrum and traditional VCT-ers at the other. De Cock and colleagues, for example, continue to argue explicitly for provider-initiated HIV testing and against obtaining informed consent.<sup>6</sup> On the other hand, South African academics Crewe and Viljoen seem not to countenance any change in approach, deeming the risks of stigma and human rights violations too great.<sup>7</sup> These two poles of the debate also illustrate that the human rights argument can be manipulated to both support and oppose the routine offer of HIV testing — the outcome depending largely, in rights terms, on whether more emphasis is given to the right to life or to personal autonomy.

But on both sides, a lack of definition and agreement about what is meant by routine testing and why it is necessary to scale up HIV testing has crept in. Another mistaken trend is a tendency to artificially juxtapose rights against each other or rights against public health. For example, in an article written in 2005, Nieburg and others agree that safeguards to protect human rights must be part of the universal offer of testing and counseling, but warn that procedures that safeguard a patient's autonomy at the expense of his or her health and well-being undermine the moral and logical basis of human rights themselves.<sup>8</sup>

Nieburg and others reflect on the origins of the "defensive approach" to HIV testing but neglect to explain that, historically, this approach was as much a part of the public health approach to HIV as today's more expansive approach should be. As described by Kirby, the idea was that by respecting the rights of those infected or disproportionately vulnerable to infection you made it possible to interrupt the potential chain of new HIV infections.<sup>9</sup> Thus, although only routine testing specifically links itself to the right to access treatment, both approaches have found a rationale in improved HIV prevention. The difference is that the social and medical

terrain in which routine testing is proposed has changed dramatically — there are millions more people infected with HIV and medical breakthroughs have made HIV a chronic manageable disease, rather than an invariably fatal one.

Unfortunately, without locating the changed approach to HIV testing fully in the social context, Nieburg and others' argument (which is respectful of the right to autonomy) risks being conflated with the viewpoint articulated by De Cock and others who insisted even before the advent of ARV treatment that the entrenching of the right to informed consent — in my view still a guarantor of respect for dignity in the process of HIV testing — was (and remains) the primary barrier to access to widespread HIV testing.<sup>10</sup>

This argument artificially pits a person's right to autonomy against his or her right to health and well-being — as if the two can be separated. It leads down a dangerous road — away from the principle that a human rights approach will complement and strengthen a public health approach.

In my mind, the correct approach lies somewhere between RCT with the "right" to opt out and VCT, which depends on individuals overcoming fear and stigma to voluntarily "opt in." Providing the resources and personnel for scaling up of HIV testing (achieved through routinely offering HIV testing and encouraging people to be tested) is a positive duty of the state necessitated by the consensus on the human right to health. Pre-test counseling and public education should henceforth be more directive in recommending that people seek and accept the offer of an HIV test.<sup>11</sup> Conversely, creating a presumption that you will be tested unless you opt out runs counter to the human right to autonomy and the ethical duty of health workers to obtain informed consent.

I believe that, instead of arguing that the requirement of informed consent has been raised to an unjustifiably high level for HIV care ("AIDS exceptionalism"), we should assert that it has been tolerated at a low level for other communicable diseases, including tuberculosis. Empirical evidence can be evinced to support the claim that the global failure to treat these diseases with respect for human rights, especially autonomy and dignity, is a major factor explaining the failure of their control.

## **From Debate to Implementation**

In conclusion, therefore, it must be argued that improving health service capacity to permit the routine offer of an HIV test is a duty that faces governments. But if routine testing is to be successful in preventing and treating millions of HIV infections, it is important for its advocates not to forget the reality that, for the past 20 years, the primary barriers to large-scale utilization of VCT were stigma, lack of access to facilities for VCT, and a belief held by doctors and patients alike that it is better “not to know” (because of the lack of treatment and pervasive discrimination). None of these factors have, by any means, been eliminated. Consequently, a move toward the routine offer of HIV testing that is genuinely grounded in human rights demands that these issues now be addressed tangibly and urgently because they remain integral to effective HIV prevention, care, and treatment.

Another danger is overlooked at our peril. The routine offer of HIV testing risks being driven by expanding access to the technology of HIV testing (rapid tests, for example) while continuing to limit access to counseling, as is largely the case in Botswana. In this scenario, the danger is that the missed opportunity for pre- and post-test counseling will impact negatively on a person’s coping ability as well their prospects for adherence to treatment — thus ultimately undermining health and well-being.

By contrast, the routine offer of HIV testing with a continued emphasis on counseling as the gateway to informed consent necessitates training community health workers in counseling that is sensitive to human rights and ethics in the practice of medicine. It also requires that the state play a much greater role in making health information available in order to increase treatment literacy and understanding of HIV. If vulnerable populations (rather than just experts) better understood the social and medical causes of the epidemic engulfing them, it would reduce the responsibility that presently falls on health care providers to convey large amounts of information in an impossibly short time.

Finally, it is necessary to caution those who approach routine testing as a beneficent way to allow health care

workers to prosecute a new “war on AIDS” with the main objective of getting people onto treatment. From a human rights perspective, routine testing also carries the risks of becoming a war on “vulnerable groups” — and later on, people with HIV — who must be identified so that the state can “help them” (allegedly). This is paternalistic and coercive; and if the objective is improved HIV prevention and treatment, then routine testing will most certainly fail. This approach might work where the medical intervention is as straightforward as a single vaccination, such as with the global campaign to eradicate smallpox. But HIV is a complex social disease as well as a pathogen. HIV prevention and treatment require long-term changes to patterns of human behavior, not short-term fixes.

## References

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10. De Cock, Marum, and Mbori-Ngacha (See note 5).
11. It is interesting to note that subjecting the question to a purely ethical analysis also reaches the same conclusion. See T. Metz. *The Ethics of Routine HIV Testing: A Philosophical Analysis* (Research paper prepared for the AIDS Law Project, March 2005). Available at [www.alp.org.za](http://www.alp.org.za).