

**4th IAS Conference on HIV Pathogenesis,
Treatment and Prevention
HIV Testing – Increasing Access, Increasing Uptake,
and Protecting Human Rights
International AIDS Society
and Australasian Society for HIV Medicine
July 24, 2007**

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CHRISTINE GRADY, R.N., PH.D.: Good afternoon. Thank you for coming to this session on "HIV Testing, Increasing Access, Increasing Uptake and Protecting Human Rights." My name is Christine Grady. I work in the United States NIH in the Department of Bioethics and I'm one of the co-chairs for this session, and my fellow co-chair is -

WILLIAM O'LOUGHLIN: Good afternoon, I'm Bill O'Loughlin, I work as a consultant. And I think I'm involved in this because I recently wrote a paper for UNAIDS about testing and counseling in the Asian region.

CHRISTINE GRADY, R.N., M.D.: Thank you. I'm just going to start by a couple of remarks to frame the issues that are going to be discussed today. As everyone in this room knows quite well, HIV testing is essential. For people to be able to know their HIV status and thus to have access to treatment and care and support and also to take steps to protect others. Yet, it's estimated that less than 20-percent of people globally that are infected know that they're infected. Why is that? Certainly testing has not been as widely accessible as we hope it will be in the future, and also people have been afraid of testing for a variety of reasons - stigma, discrimination, even violence against them, all very real and tragic phenomena.

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In the roughly two decades since we've had the HIV test, it has been surrounded by lots of issues. Issues related to public health, ethical issues, human rights issues. We've debated, we've argued about mandatory testing, fought for anonymous testing, ultimately settled on widespread voluntary testing and counseling. There have been disagreements, agreements and various laws about who to test, when to test and who has access to test results. And the spectrum has run from no consent to full written consent, from opt in consent to opt out consent. In an effort to increase access to and uptake of HIV testing, recently in many parts of the world, there has been growing support for an implementation of what's called provider initiated testing and counseling.

Today, we are very lucky to have with us a very distinguished panel of speakers, who will discuss guidance for, experience with, concerns about and perspectives about provider initiated testing and counseling. So without further delay, I'm going to introduce our first speaker.

Our first speaker is Dr. Kevin De Cock, who is the director of the WHO Department of HIV/AIDS, where he oversees all of WHO's work related to HIV/AIDS, focusing on initiatives to assist developing countries in scaling up their treatment, prevention, care and support programs. Dr. De Cock is an infectious disease specialist with expertise not only in

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HIV/AIDS but tuberculosis, liver disease and tropical diseases such as yellow fever and hemorrhagic fevers. Dr. De Cock will discuss the WHO guidance on provider-initiated testing and counseling.

KEVIN DE COCK, M.D.: Thank you very much, Christine. Colleagues, friends, good afternoon. I'd like to start just by thanking the organizers for inviting me to speak at this session on HIV testing. Years ago, I heard a recording of a talk given by one of my co-panelists Honorable Justice Kirby, at an international AIDS conference where he introduced his remarks by reminding listeners of the grave implications of disagreeing with a judge. I hope that on this panel we will agree that even with different life experiences, I think there's much more that binds than divides us today, and perhaps especially in our belief in the ideal of universal access.

In my 10 minutes, I'll cover some historical points on testing and counseling, review of current status and its consequences, highlight some essentials of the recently released guidance on provider-initiated HIV testing and counseling, and finish with some thoughts for the future.

I represent the World Health Organization, but I speak as a simple physician. Committed to clinical medicine and public health, guided by fundamental principles of those disciplines that are respectively for clinical medicine,

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diagnosis, and for public health, social justice. Guided by notions of rights, most importantly, the right to life and the right to health, and by medical ethics, and concern that my profession do the right thing. The right thing, not in the words of Martin Luther King, in moments of comfort and convenience, but in moments of conflict and controversy.

The right thing in medicine includes basing decisions on evidence as well as good judgment, assuring decency so that others are treated as one would wish to be treated oneself. Promoting sound health policies and recognizing always with humility that the Hippocratic notion of "do no harm" is not compatible with inactivity in the face of remediable threats. A serologic test was licensed for the first time for HIV in 1985. To avoid persons seeking knowledge of HIV status through donating blood, voluntary counseling and testing was introduced and emphasized from the beginning consent, confidentiality and counseling. In the early '90s, ACTG076, showing two-thirds reduction in perinatal transmission of HIV, led to greatly increased, more routinized antenatal HIV testing in the industrialized world.

The advent of combination ART in 1996 further enhanced this, but practice in developing countries lagged behind. A document from WHO in 2003 entitled "The Right to Know" endorsed the concept of opt-out HIV testing in clinical settings, and

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was followed in 2004 by a Joint UNAIDS WHO policy statement that recognized different reasons for testing and different approaches. This statement, however, failed to gain traction because of lack of follow up and some ambiguity.

On May the 30th of this year, WHO and UNAIDS issued new and detailed guidance on provider-initiated testing and counseling to guide countries on HIV testing in healthcare facilities in the context of HIV service scale-up. And of course CDC in the United States had issued guidance on this subject in September of last year.

Globally, knowledge of HIV sera status is low. In 12 African countries, but Asia is little different, only 10-percent of women and 12-percent overall of men had been tested for HIV and received their results. Only about 20-percent of HIV positive Africans are aware of their HIV infection status, shown here in these different countries. Only about 10-percent of pregnant women in all low and middle income countries are accessing HIV testing, the median estimate for 10 countries that contribute two-thirds of the world's HIV-positive pregnancies, the median of those countries being less than 20-percent. And only 14-percent of patients with tuberculosis worldwide received an HIV test in 2005. What does it mean under such circumstances to speak of universal access?

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The consequences of lack of knowledge of sera status are measurable in failed prevention, disease and death. Despite impressive scale-up by end of 2006, treatment coverage globally was only 28-percent, meaning that over 4 million persons worldwide, the unmet need in brown on this slide, failed to access therapy. Lack of testing is a major, though not the only barrier. Children and injecting drug users are especially underserved and diagnosis of children severely lags behind.

Ample data show poor treatment outcomes when ART is initiated late. The typical situation in the resource-poor South where mortality, especially in the first months, is more than four times higher than in the north. Overall, about 2 ½ times higher. Seventy-three-percent of these deaths in these developing country cohorts were in person whose CD4 counts at treatment initiation were below 100 per cubic millimeter. Thirty-eight-percent of the deaths occurred in the first month, 80-percent in the first four months. Delayed HIV diagnosis clearly is bad for your health.

And all is not well in the industrialized world either. In the United Kingdom, approximately one-third of all newly diagnosed persons shown in green had a CD4 count below 200 around the time of their first HIV diagnosis. A substantial proportion of people in industrialized countries first learn of

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their HIV infection when they develop a preventable AIDS defining illness, and HIV testing policies are under discussion there, are indicated by these articles in a recent issue of the *British Medical Journal*.

Increasing knowledge of sera status in different ways if therefore important for increasing treatment access, improving outcomes and enhancing prevention, including PMTCT. On the 30th of May of this year, WHO and UNAIDS released this document, *Guidance on HIV Testing and Counseling in Health Facilities*, to provide a device in the context of often unclear, sometimes suboptimal practice internationally, and to increase HIV testing in appropriate clinical settings. It results from extensive consultation, including a Web-based public comment period. The guidance states that everywhere in the world, in all epidemic types, HIV testing and counseling should be recommended to patients whose clinical presentation could result from underlying HIV infection, including patients with tuberculosis, and for all children born of HIV infected mothers. This recommendation for testing should ordinarily lead to the test being performed unless the patient declines.

The WHO and UNAIDS guidances advises that in generalized epidemics, HIV testing should be recommended to all persons attending healthcare settings, irrespective of the reason for consultation. Implementation of this recommendation

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can be phased in progressively with prioritization of settings such as medical clinics and wards, maternal health services, STI clinics, et cetera.

The guidance recommends more targeted testing for concentrated epidemics. In such settings, testing is not recommended for all health care attenders, and priority should go to recommending testing for persons potentially symptomatic from HIV or children born to infected mothers. With appropriate conditions, testing could be systematically recommended in settings where HIV-infected persons are known to be disproportionately represented, including STI clinics, services for injecting drug users, et cetera. When resources permitting, countries may decide to prioritize antenatal services for the prevention of mother to child transmission.

The recommendation for HIV testing should not be coercive or construed as mandatory. HIV testing should not be conducted against patients' will, without their knowledge, without information, without counseling around results, and without linkage to appropriate services. As with all procedures, decisions around testing should always be in the best interest of the individual patient, and inclusiveness, consultation, and careful adaptation to local conditions are necessary.

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Monitoring and evaluation should lead to response to documented problems. Some countries are ahead - Botswana, Malawi, Kenya and Zambia are some examples of leadership in implementing PITC. Other countries and their civil societies, including and perhaps especially in Asia, should consider their best options. The benefits of not adopting this guidance, perhaps to prevent or minimize discrimination and stigma, for example, must be weighed against the unforgiving outcomes of undiagnosed progressive HIV disease and preventable transmission. Whatever one decides, there is no escaping ownership of the outcomes of that particular decision, be it for example physical violence to a woman disclosing her HIV status or undiagnosed fatal HIV disease in a family.

We believe this guidance offers balance and opportunity to normalize HIV and its management in health care settings, without which, talk of universal access is a hoax. Finally, WHO and UNAIDS also strongly endorse expansion of client-initiated HIV testing and counseling and these two approaches should not be portrayed as alternatives or in conflict. Both should contribute to the clinical and public health imperative to scale up knowledge of HIV sera status everywhere that HIV is a threat. Thank you.

[APPLAUSE]

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WILLIAM O'LOUGHLIN: The second speaker is Justice Michael Kirby, who was appointed to the Australian High Court in February 1996. At the time of his appointment, he was president of the New South Wales Court of Appeal, having been appointed to that office in September of 1984. He was admitted to the New South Wales bar in 1967 and appointed Deputy president of the Australia Conciliation and Arbitration Commission in 1975. He served as first chairperson of the Australian Law Reform Commission from 1975 to 1984. In 1983, he became a judge of the Federal Court of Australia, serving on that court until 1984. He has held numerous national and international positions, including being on the Board on CSIRO, as President of the Court of Appeals of the Solomon Islands, as UN Special Representative in Cambodia, President of the International Commissions of Jurists [inaudible].

THE HONORABLE MICHAEL KIRBY, LL.M., A.C., C.M.G.: Oh, yes, yes, we know all that.

[Laughter]

THE HONORABLE MICHAEL KIRBY, LL.M., A.C., C.M.G.:
Thank you very much, Bill. Ladies and gentleman, as the token Australian on this panel, I want to welcome all those who come those long distances to Australia for this conference and seen what we have to put up with every time we come to visit you. So, welcome to Australia.

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Now, if this AIDS conference in Sydney does nothing else, it has to send a clear message repudiating the suggested conflict between the human rights and the medical approach to the AIDS pandemic. In this struggle, there's obviously a most vital part for medical science, and it's increased since the antiretroviral drugs became available. But as we all know, those drugs don't cure HIV or AIDS. There's no cure, no vaccine and none seems immediately imminent. In these circumstances, there's more than enough for medicine and social science, even occasionally the law, to do together. For the foreseeable future, each has to play a harmonious role. Neither alone can fulfill the task unsupported by the other.

So we've got to stop any thought of the so-called remedicalization of this epidemic, of reclaiming HIV and AIDS for the doctors, or of abandoning the rights-based approach to the challenge to our species. When Jonathan Mann, who is still vivid in our memories, taught us in the earliest day of AIDS that we must take this rights-based approach, he gave a lesson which is still relevant. AIDS is not, and probably never will be a neutral medical condition. Indeed there are still two epidemics, the epidemic of the virus and the epidemic of stigma. We can reduce both, but for this we have to tackle them both and at the same time. There's no pill that can be popped by an individual that cures social alienation that lies

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at the heart of stigma, which is xenophobia, racism, homophobia, denial, ignorance and fear. It's important to say all these things, because when ARVs came along, the demand to reclaim the epidemic and to expel the rights based scientists was unmistakable in some writings. We all know how the argument went, after all it was pretty difficult in the early days to get our minds around a new approach to such a dangerous epidemic.

In the initial absence of effective drugs, the social scientists, with their imperfect techniques of behavior modification had to be given a free hand. We know this in Australia because we did it and we did it better than most. We decriminalized homosexual offenses, we reformed the law on commercial sex work, we embraced syringe exchange, we enacted laws against discrimination, we promoted condom awareness, including in schools, and so on and so forth, and our spread of HIV went down.

Now, we all know that most countries will not or could not do these things, or so they said, and the UN endeavors to get nations mobilized along these lines have largely fallen on their fears. Platitudinous but particularly powerful talk of so-called ABC devoured huge funds most ineffectively.

[APPLAUSE]

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If there had been one reprehensible failure in the first quarter of this epidemic, it's been the willful blindness of so many political leaders and the incapacity of the United Nations machinery to demand and secure strategies that are essential to treat the epidemic of stigma. This is a true disgrace to humanity. Blindness and incapacity remain today. It may be explained by reference to cultural diversity and religious principles and so on, but it can't be justified, given the rapid accumulation of knowledge about this epidemic and the effective strategies that work against it.

Yet when the ARVs appeared, demands arose to treat this epidemic as a medical condition, as if popping a few pills would make HIV and AIDS go away without the irksome necessity to face up to the stigma. What a tempting bait for these politicians and bureaucrats living in denial. The problem with the argument is that like [inaudible], it was partly right and partly wrong. It was partly right because ARVs properly administered do give an often immediate help and hope to people who are profoundly sick. They do indeed sometimes reduce stigma. Getting out to millions the now available therapies is, as Kevin De Cock has rightly said, a basic human right for the infected. And promoting the ordinariness of testing may stimulate the first steps towards personal responsibility.

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But a culture of widespread testing is itself never going to be a miracle cure for this epidemic. This is something that social scientists have to keep on telling medical science, taking the benefit of the test without more produces no benefit. Indeed, at the time when criminalization of HIV transmission is on the rise, provider initiated testing, once reported, can expose those tested to the very serious risks of criminal liability and punishment. This happens. I can tell you. I've sat in cases involving this in Australia. Testing without attacking the causes of stigma presents real risks in most parts of the world of subjecting those found HIV positive to a double burden.

The effectiveness of current ARVs, future costs of second line therapies mean that a strategy of treatment alone is one that may only work for the comparatively short term. Most fundamentally, the Hippocratic oaths in ancient times and in modern times, and the fundamental notions of health care ethics, usually reinforced by local and international law, demand affirmative patient consent to significant medical procedures, of which HIV tests are certainly one.

So herein lies the big dilemma of HIV testing as it presents today, but from the very beginning, AIDS has been full of dilemmas and this is just the latest one. The way for us to deal with this dilemma and paradox is not to deny it, nor to

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endorse medical triumphalism, and unless we can put a new effort into prevention, all the tests in the world and all the pills we can offer will not keep pace with the oncoming avalanche of seroconversions. Nor will we resolve the paradox by embracing weasel words and ambiguous text that pretend to endorse patient consent to HIV testing when in truth, we impose mandatory testing of highly vulnerable persons, [inaudible] who depart the moment of discovery that they're HIV-positive and rejoin the world of stigma, fear and exclusion.

So what's the conclusion? There's a need for social scientists to recognize that the potential mass availability of ARVs has indeed changed the dynamics of AIDS. There's a need for the health care proponents of stepping up screening for their part to face the hard necessities that have been with us from the very beginning of this epidemic, to tackle stigma and discrimination with exactly the same and even greater energy than we tackle testing and treatment, to adopt the sometimes uncongenial but essential measures to respond to stigma, and to introduce any provider initiated screening for HIV with full patient participation and respect for the patient's fundamental human dignity and human rights. In short, stepping up testing has to occur in proportion with testing up legal and social measures to combat or address stigma.

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So far as most countries, governments and officials have embraced testing and therapies, they do so at least in principal. But they have failed abysmally to tackle the second epidemic of stigma. We all know that the human mind is a most curious beast. Every day it lives with paradoxes, and so we have to solve this new one. The way to do so is to recognize that AIDS evolves from the skills of medical science and the practical strategies of social science. From the start, this epidemic has been different and unique.

As we're rightly stepping up testing, it would be shameful and ultimately self-defeating in my view, if we failed to step up the measures against stigma and discrimination. And if we ignore the integrity and basic rights and autonomy of the individual, we will be knowingly involved in a significant decision, and HIV testing is certainly a significant decision for the persons concerned.

Now, Kevin De Cock said at the beginning of his remarks that he didn't think that this panel would have great differences between themselves. I've listened to Kevin, I've looked at the WHO and UNAIDS guidelines. We helped and participated in the evolution of those documents. They are step in the right direction, but it is important that it be said loud and clear no UN agency can ever be involved in anything which departs from the fundamental principles of

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international human rights law. They are the principles that found the United Nations, and we must uphold them at all times.

[APPLAUSE]

CHRISTINE GRADY, R.N., PH.D.: Thank you very much, Justice Kirby. Our third speaker is Bernard Branson, who is currently the associate director for laboratory diagnostics in the Division of HIV/AIDS Prevention at the Centers for Disease Control in the United States, where he also conducts research into HIV prevention strategies. Dr. Branson has been the chief architect for CDC's activities surrounding new technologies for HIV testing, including rapid HIV tests, and tests for HIV incidence. Dr. Branson will discuss implementing U.S. testing policy, CDC's experience, and lessons learned.

BERNARD BRANSON, M.D.: Thank you, Christine. My presentation will go in a bit of a different direction from the others, because this has to do with some of what our experience has been in implementing our recommendations.

First thing, I wanted to just review a small bit about the U.S. epidemic. We estimate that in the United States, between 1 and 1.2 million people are infected with HIV, and of those, about a quarter, somewhere between 250,000 and 300,000 people, are unaware of their infection. We estimate there are approximately 40,000 new infections a year, and consistently over the last 10 years, approximately 40-percent of the people

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who are diagnosed with HIV develop AIDS within a year of their first HIV diagnosis. In addition, the epidemic in the United States is not evenly distributed. These are data from the National Health and Nutrition Examination Survey, a nationally representative household based survey of the U.S. population, and if you look at the black bars in both the younger age group, 18 to 39, and in the older age group 40 to 49. The blue bar is representing black men. And we see that the prevalence in younger men is nearly 2-percent. The prevalence in older black men is nearly 4 1/2-percent. These are very similar to some of the figures I've heard reported today from recent surveys in Uganda.

Similarly, among black females in the younger age group, nearly 1-percent are infected. Black females in the age 40 to 49 age group, nearly 3-percent are infected in the United States. And so we consider this a significant problem, and it is not a matter of being a minimal condition in the U.S. for HIV.

In September of 2006, CDC published revised recommendations for HIV testing of adults, adolescents and pregnant women in health care settings. And I emphasize that these recommendations applied to health care settings, because our experience was that many people were passing through health

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care settings in the United States with HIV that remained undiagnosed, despite multiple visits in health care.

The terminology in these recommendations are very explicit. One has to do with screening. Screening is performing an HIV test for all persons in a defined population. This was different than our earlier practice of targeted testing where we focused our testing activities only on certain people perceived to be a high risk. We also recommended opt-out screening, which is performing an HIV test after notifying the patient that the test would be done, giving them the opportunity to ask questions, and the option to decline and that consent would be inferred unless the patient declined.

The recommendations call first of all for a routine voluntary HIV screening for all persons aged 13 to 64 in health care settings, regardless of risk. In settings with low or unknown prevalence, and that's most of the settings in the U.S., unknown HIV prevalence, we recommend that screening be initiated and if the yield from screening is less than one infected person per 1,000 screened, then continued screening would not be warranted.

We recommend opt-out HIV screening with the opportunity to ask questions and the option to decline testing, but that separate signed informed consent in health care settings should not be required, where most people already sign consent for the

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treatment they will receive. We also indicated that prevention counseling in conjunction with HIV screening in healthcare settings should not be required. This is not to discourage prevention counseling but to indicate that it was the circumstances of the patient rather than the issuance of the test that would be an indication for prevention counseling.

We stress that screening must be voluntary, that all patients must be informed, orally or in writing, that HIV is planned and will be performed unless they decline, and that like the WHO recommendations, it is essential to arrange access to care, prevention and support services for patients with positive HIV test results.

What I would like to do is review a few of our initial experiences with these recommendations, some of them leading to the issuance of these recommendations. First of all, in New York City, the Health and Hospital Corporation, the largest provider of healthcare to indigent persons, set a goal to increase testing from their baseline of approximately 50,000 tests per year in 2003 to 2005. The intended target was to increase the number of patients who know their HIV status, and this was conducted in New York State, where there is a revised two-part consent form and signed informed consent is still required. This looks at the experience in New York, where in fiscal year 2006, they nearly accomplished their target of

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doubling the testing from 50,000, in 2007 made further progress to conduct 132,000 tests a year. This represents a nearly 70-percent increase over their average in 2004 to 2005.

Importantly, they also doubled the number of people who were diagnosed with HIV passing through their institution from approximately 700 people a year to between 1,500 and 1,600 people a year at the current time with this expanded testing.

In San Francisco, San Francisco Public Health had a regulation in place which required signed informed consent, and that this consent be documented on the requisition that was sent to the laboratory. When the first draft of the CDC's recommendations was circulated in May 2006, San Francisco Public Health changed their requirement for signed informed consent so that a separate consent was no longer required, and HIV testing was added to the regular lab requisition. They compared their rates of testing and new HIV diagnoses, before and after the change. And what you see here is that after the change in May 2006, the rate of testing increased in their health clinics and in the public health hospital. The number of HIV diagnoses increased from a mean of 20.6 positive tests per month before the change to 30.6 HIV-positive tests after the change, which provided some at least ecologic evidence that it did make a difference whether or not you required this separate document.

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We have some experience as well in emergency department HIV testing programs. This was one that began in the Cook County Hospital in Chicago in 2003, where screening was initiated and 62-percent of people accepted HIV testing. Because rapid testing were used, 98-percent received their test result. Initially, 3,300 patients were screened. Eighty-three, or 2.5-percent of the people coming to this emergency department for reasons other than HIV were found to be HIV infected. And importantly, 80-percent of them entered HIV care in the median of 18 days after receiving their test result. Approximately half of these people had no identified risk factors and 57-percent of these people had never been tested for HIV before. But we also have compared, because in this setting there was some *de facto* screening in a disease setting, or *de facto* targeting, so that providers referred patients as well as send routine screening.

So those who referred by providers represented only 10-percent as many as who were screened routinely, the acceptance of testing was very high among provider referred patients, 95-percent compared to 58-percent screened routinely, and the providers were very astute in picking up HIV infection. Nearly 12-percent of the patients they referred were infected compared to 1.2-percent of those who were screened. However, the patients that providers are going to find were much sicker.

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Seventy-one-percent needed to be admitted to the hospital compared to 54-percent among those screened routinely, and 82-percent had immunologic AIDS, CD4s of less than 200 of those referred by providers, compared to 45-percent of those routinely screened. And nearly half, 42-percent of the HIV infected patients would be missed, if routine screening had not been in place.

We've conducted ED screening projects in several other jurisdictions. In Los Angeles and New York, it was a counselor-based system, where counselors offered and performed the rapid tests and performed pre and post test counseling. An alternative was in Oakland where a triage nurse offered the test and the ED staff, usually the nurses, performed the rapid test and disclosed the test results. If you look at these institutions, in Los Angeles and New York and in Oakland, between 50,000 and 70,000 patients had presented. Testing was offered, however, to only 1,500 patients in the counselor-based models, compared to 31,000 patients in the routine models. Acceptance was very high when counselors had offered testing, nearly 98-percent. Only 52-percent when it was routinely tested. And the number of patients actually tested was considerably lower than those who accepted in a busy emergency department, but the bottom line here is that in the counselor-based models, in these busy institutions, in Los Angeles, 13

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patients were identified. In New York, 19 patients were identified. In Oakland, nearly four times as many, 65 HIV infected persons were identified, with the same prevalence in all those environments.

In Oakland, they conducted a patient satisfaction survey among the HIV-positive patients and those who were negative. Of those who were positive and responded to the survey, 100-percent said that they were satisfied with the process, and 96-percent said that they felt the result disclosure was private. Among those who were HIV-negative, 99-percent said that they were satisfied with the testing process in the emergency department, and 91-percent felt that the disclosure was private. This was in a circumstance where the perception of privacy was maintained, despite testing and disclosure of the negative test results in a variety of clinical areas in the emergency department, sometimes separated from other patients only by curtains.

In George Washington University Hospital in Washington, D.C., opt-out screening was conducted between September and December 2006. They also interviewed patients and conducted surveys. Six hundred eighty patients were interviewed, 70-percent who accepted the test, 30-percent who declined. And the question that's asked is, what do the patients think? One question was is the ED a good place to perform testing? And as

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you see here, 73-percent of the patients either agreed or strongly agreed that the emergency department was a good place to perform emergency department testing, and 84-percent of patients said that they would recommend that a friend get an HIV test if they went to the same emergency department.

We're encouraging all of our programs to poll these patients to find out what people perceive in addition to what the providers and CDC perceive. In summary, we think there's an urgent need to increase the proportion of persons who are aware of their HIV infection. With streamlined programs, we find that more patients are tested, more HIV infections are diagnosed, and that most patients approve of HIV screening.

I would like to acknowledge in particular some of the people who provided unpublished data for this presentation, including the New York Health and Hospitals Corporation, the George Washington University Hospital and the Alameda County Hospital in Oakland, as well as numerous CDC colleagues and collaborators. Thank you.

[APPLAUSE]

WILLIAM O'LOUGHLIN: Thank you. I think I should explain, we're going to continue with all of the speakers in the program, and that will allow for about 30, 35 minutes at the end for a question-and-answer and discussion.

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Our next speaker is Promise Mthembu from South Africa. As an HIV/AIDS activist, Promise is currently working for the International Community of Women Living with HIV and AIDS as Global Advocacy Officer for Sexual and Reproductive Rights. She co-founded and coordinated the Young Positive Living Ambassadors Program, which addresses human rights and gender issues affecting youth living with HIV, and mainstreaming HIV in youth development work. She's worked with a treatment action campaign in Africa as coordinator of PMTC program. And she's lived positively with HIV and AIDS for the past seven years, and is passionate about issues concerning young people with HIV. Thank you.

PROMISE MTHEMBU: Thank you for the warm introduction. I would like to thank the International AIDS Society for inviting me to be part of this panel today. I've been asked to present the perspectives of people with HIV in the area of HIV testing, but I feel incompetent to put forth perspectives of people with HIV in this area. I would rather focus on what I'm familiar with, the issues of women living with HIV as they relate to HIV testing.

As women living with HIV, we feel that HIV testing is good because it gets people to know their HIV status, and it sometimes can lead to people accessing care and support. But the biggest question we have is that who should be making a

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decision about a person getting tested for HIV? And our human rights codes inform us that an HIV test should be an individual's choice and decision, people should decide whether or not they want to take an HIV test.

It is important to acknowledge that the global HIV and AIDS field has been moving quite rapidly insofar as making HIV and AIDS testing accessible. In a couple of years' time, a couple of years ago, they introduced what was known as voluntary testing and counseling, VCT. Whether VCT was voluntary or not is another matter, but what we've seen is that before evaluating VCT, the global AIDS response has embarked on what it calls the provider initiating HIV testing. We viewed this intervention as problematic in many respects. One is, it does limit the individual's choice on whether or not to take an HIV test. And how does it do this? It talks about opting out, and we feel that in talking about opting out, it ignores the fact that there is power in balances between the service provider and the service user.

We know from the world we've been doing around the world and the Gender AIDS Forum are with us on this, that women, particularly HIV-positive women see healthcare provision centers as places of powerlessness. They report that they lose their power the minute they think about going to clinics. Then

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we ask, how then is this woman expected to make a decision of opting out of an HIV test?

We also are aware given our experience of working with health care workers that health care workers do not see themselves as recommenders, but they see themselves as advisors because they carry a [inaudible] of providing health care services to the people who are presumably ignorant. So we don't see how a health care worker can recommend something we see them advising. And it's also difficult for people not to take the advice of the health care workers, because they risk not accessing services or being stigmatized or [inaudible] in health care settings.

What this all means is that this testing that has been introduced is being forced upon people. It is therefore compromising the people's rights to choose how and when to be treated in healthcare settings, and it also undermines the people's rights to their body's integrity.

What is also disturbing us and worrying us is that this new intervention is founded on some assumptions that have not been tested, because we have been calling for evidence on these assumptions but haven't received any. The advocates for such testing are saying that if you expand HIV testing, you stand to reduce the rate of HIV infection. And we ask, how is this going to happen, and where is the evidence? We'd like to see

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the evidence. How does me knowing my status reduce the rate of HIV infection if the vulnerability of the other women in that town where I come from still stands as it is?

They also claim that expanded HIV testing will reduce the HIV related stigma, and here, we ask, how is this going to happen? Is this expanded HIV testing not full of stigma anyway? Who gets targeted for this sort of testing? Is it not those who are perceived to have the HIV virus? Is the very act of imposing a test not stigmatizing against people? And I'm thinking of a scenario where I go to the clinic today and I get offered this HIV test where it's said that I might wish to opt out, and then I go back to my communities to say hello - oh, I, I'm Promise Mthembu. I was at the clinic today and I was offered an HIV test. What sort of response am I to expect from my communities? Are they going to accept me, or are they going to stigmatize me? Because the very fact that I've been offered a test does suggests that I might have HIV. Is it not stigmatizing me even further? And is this something that people are happy to go back to their communities and families and talk about, or do they go back and keep quiet about it? Is it okay to share such information? How does the stigma reduction happen? We are assuming that if we test more people stigma will just disappear, just by the virtue of people knowing their HIV status. And we ask, why does it become a

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concern of a health worker whether I wish to know my HIV status or not? What happened to the idea that pain is better to find by a patient? Why is the health system not seeing me as a holistic person with issues, concerns and priorities as someone who's able to prioritize what I need at a particular time?

There's also an argument that is being pushed forward in advocating for this provider initiated HIV testing. You know, they say that it's going to expand access to care, treatment and support, and we feel that this is a miscalculation and it's misleading.

Where I live in Southern Africa, there are reports that less than 50-percent of people needing treatment do not have access to such treatment. We still see AIDS deaths at alarming numbers, and these are people who have tested more than a decade ago, and these are people who have tested before VCT and PITC came into being. They are not dying because they were never tested. They died because they do not have access to adequate treatment and care. They died on waiting lists. They died because of lack of adequate care, other than ARVs. They died because of [inaudible] cervix, they died because of TB, they died because of pneumonia. They died because of social barriers to access to treatment. They died because of gender barriers to access to treatment. And they died because of individual barriers to access to treatment. And they died

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because they don't have access to line 2 and line 3 of treatment. And we ask - are we then saying that if we test more people, the rate of death is just going to disappear just like that? What about these issues that are stopping people who need treatments, people who have tested a long time ago, from [inaudible] treatment to access them.

And we ask, why are we increasing the number of people who are in treatment ranks if you are failing to deal with the number that you already have? And whose agenda are we serving really? Are we serving the statistics agenda or are we serving the healthcare provision agenda? What are we going to do with these numbers, and what do these numbers do insofar as responding to HIV and AIDS is concerned?

And in our work working with HIV-positive women, an HIV test has some responsibilities attached to it. As we said, it can be good but it can also be quite destructive, which is why we see it as a doubled edged sword. And our concern is that the global response to HIV and AIDS has been ignoring the destructive contributions of HIV testing. We behave like HIV testing evangelists. We want to push it, even if we know that it can be harmful, if we know that it's not going to work, even if we know that it's not addressing the issue at hand. You know, but we preach it over and over and over again and that is problematic. We know, for example, that an HIV test or

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positive result can increase a woman's vulnerability to violence. And we know that a woman who has tested positive for HIV will receive less societal sympathy if that woman has been violated. We know that if a woman, two women are raped today, and the other goes and says, I was raped this morning, and I also have HIV. And the other one says I was raped and I don't have HIV. We know that the woman who has HIV is not going to receive the same quality of treatment and police support, and her case might not even get to court. But it's like we ignore all of that when you talk about HIV testing. We know that there are linkages between HIV and violence against women [inaudible] post-testing, and we do not push support for these women that get marginalized and not get services just because they have HIV.

We know that the HIV testing interventions are recommending referring women to organizations such as those working with gender-based violence, but we ask, what do those organizations have? I mean, what expertise do they have to work with HIV, and where are the resources to support these organizations who are now picking up the burden that has been created by HIV testing? If we know that it's harmful, why are we not putting in place measures to deal with harm? Why are we just pushing without being cautious of the negative consequences that it might lead women to?

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And in closing for my talk, I'm going to take all the negative things as far as HIV testing is concerned, and we wish to recommend the following to WHO, and those who are with WHO in advocating for expanded HIV testing. We call upon WHO and the advocates for expanded HIV testing to live up to the agreements of human rights in health. We are concerned that the hunger for statistics and numbers is compromising the rights in this area, and we call for rights first please.

We also call upon the advocates for HIV testing to commit themselves to working towards advancing women's rights in health as opposed to undermining the rights which have been negotiated and agreed upon in this area. And we actually call on the WHO to document the rights lost and bargained away in HIV testing settings. We are prepared to call for redress of these rights to be embarked upon. We believe that this is one way of enforcing people's rights in health, and we see this as a major milestone in redressing stigma and discrimination. We are sick and tired of embarking on training measures, whether it's been preachers of rights, then WHO comes and says, let's train health care workers. There should be ways of enforcing these rights so that people in healthcare settings can begin to respect people's rights.

I also call upon WHO to actually embark on evaluating all HIV testing programs using human rights and [inaudible]

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balances. We feel that evaluation is long overdue. We feel that the outcomes of the evaluation should be used to transform the global HIV testing policies and programs. And I think I would like to end there. Thank you.

[APPLAUSE]

CHRISTINE GRADY, R.N., PH.D.: Thank you very much. Our final speaker is Dr. Sheri Weiser. Dr. Weiser is an assistant professor of medicine in the Division of Infectious Disease in the Center for AIDS Prevention Studies at the University of California in San Francisco. Her research focuses on HIV prevention and health outcomes among marginalized populations in both the U.S. and sub-Saharan Africa. She recently co-lead a population-based study in Botswana and Swaziland examining gender specific barriers to HIV prevention, testing and treatment. Dr. Weiser will discuss the HIV testing experience in Botswana.

SHERI WEISER, M.D., M.P.H.: Good afternoon. One of the first countries to introduce a national policy of provider initiated testing was Botswana. Today I'll be sharing some data from our group and others that highlight some of the successes and challenges that have emerged in the implementation of the policy.

I'll begin with some background on the policy itself, and then we'll review results from a population-based study we

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conducted in 2004. Next, I will briefly summarize more recent studies, and since data are still limited, I will end with a summary of unanswered questions.

Botswana is a high-prevalence country, and was the first in Africa to introduce a program of widespread access to free antiretroviral therapy. In 2004, Botswana was also the first in Africa to introduce a national policy of provider initiated testing, and this was in part in response to slow enrollment in treatment. This policy has usually been referred to in Botswana as routine HIV testing, and that's the term I'll use in this talk.

Key features of Botswana's policy include the right to decline the test, shortened pre-test information sessions and a stated goal of informed consent. You'll note that there was no systematic monitoring or detailed guidelines during the initial roll out of the policy. As a result, while the policy specified an opt-out approach, in practice it may have at times more closely resembled a routine offer or opt in approach.

Groups of people living with AIDS and some local human rights organizations raised some concerns about potential negative impacts with this policy, as we've heard today, such as that testing could be coercive, that there would be reduced counseling, that people may avoid clinics for fear of testing,

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and that this policy could lead to an increase in testing-related partner violence.

As routine testing programs are being expanded to other countries, what lessons can we learn from Botswana's experience? In late 2004, 11 months after the introduction of Botswana's policy, we conducted the first large-scale study looking at attitudes and experiences with this policy. The goals were to determine the prevalence and correlates of HIV testing, to assess knowledge of and attitudes towards HIV testing, and to compare experiences of routine testing to those of VCT.

We conducted a cross-sectional population-based study in the five districts of Botswana with the highest number of HIV infected individuals at the end of 2004. We used a stratified two-stage probability design. In total, 1,268 individual completed the survey, which represents an 89-percent response rate. I will now briefly highlight some key results. 48-percent of people said that they had tested for HIV, and that was either by routine testing or by VCR. When we evaluated correlates of testing, not surprisingly, people with more education and those who had seen their doctor more often, had higher odds of getting tested. Notably, women had 50-percent higher odds of testing, and people with stigmatizing

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attitudes towards people living with AIDS had 30-percent lower odds of testing.

Of the 664 participants who were never tested, the principle barriers were that people were afraid to know their status, that they thought they had no reason to believe that they were infected, and that testing positive might obligate them to change sexual practices.

At the time of our study in late 2004, 54-percent of participants had heard of routine testing. After a brief explanation of the policy, 81-percent said that they were very much or extremely in favor of routine testing, and 8-percent said they were somewhat in favor of the policy. Only 15-percent of participants that tested had tested by routine testing.

When we asked participants directly about their attitudes toward routine testing, the majority believed that the policy would increase access to both testing and treatment. The majority thought that the policy would lead to a decrease in discrimination towards people living in AIDS and a decrease in violence towards women. On the other hand, 43-percent thought that this policy would cause people to avoid seeking medical care for fear of testing, and 14-percent thought that this policy could, in fact, increase violence towards women.

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Comparing experiences between VCT and routine testing, overall testing experiences were quite similar as you can see. Over 90-percent that tested by either strategy said they received both pre and post-test counseling, and returned to get their test results. We also found no substantial differences in negative testing outcomes between VCT and routine testing. A striking finding though was that 2/3 of participants said they could not refuse the test, regardless of how they tested. Approximately 5-percent that tested by either strategy said they experienced a breach of confidentiality at the testing sites. Few participants reported partner violence related to testing by either strategy.

Bear in mind that our study was conducted in late 2004, and there was still limited experience with routine testing at that time. It's therefore important to review more recent data. Here's some data from a population-based study in mid-2006 by Carcroft [misspelled?] et al. Compared to our study, they found increasing awareness of routine testing, with 79-percent having heard of the policy. They found persistent support for the policy, with 94-percent in favor, and they also found that a higher proportion of people that had tested had actually tested by routine testing. Some of the most notable findings have been successes in uptake of testing and treatment.

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These data on testing uptake are from the Botswana Ministry of Health. As you can see, the rate of routine testing seems to have increased substantially between the years of 2004 and 2006. In addition, the proportion of people opting out also seems to be decreasing. Finally, it looks like people are being diagnosed at earlier stages of disease. For example, the proportion of patients testing positive with CD4 counts less than 100 decreased from 49-percent in 2003 to 34-percent in early 2006.

While we can't infer a causal connection here, two years after the policy was introduced, nearly 80-percent of HIV positive pregnant women were receiving PMTCT interventions. This was a significant increase from prior years, and is the highest anywhere in Africa. There has also been an over-fourfold increase in ART uptake, with nearly 85,000 individuals on treatment by March 2007. Please note that there were likely many factors that contributed to the high treatment uptake in Botswana.

Available evidence suggests that people don't seem to be avoiding clinics for fear of testing. In Carcroft's study, three quarters of participants reported that they had visited a government health facility over the previous year. Routine testing also does not seem to be associated with decreased use of prenatal care in Botswana.

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Despite these promising findings, there are still some concerns with the implementation of the policy. Men comprise less than one third of those tested by routine testing. This suggests that the policy may be missing out on key prevention and treatment opportunities for men. Men are not only less likely to visit government health facilities, but they're also less likely to be offered a test and more likely to opt out of testing when offered. Also, since women comprise over two-thirds of those tested by routine testing, what about concerns for an increase in gender based violence and discrimination?

Additional preliminary data suggests that there does not appear to be an increase in violence against women tested by routine testing. However, I want to emphasize here that data are quite limited, and there are no further data on discrimination related to testing.

Recent data show ongoing concerns with confidentiality and informed consent. In Carcroft's study, 10-percent of participants that visited government health facilities were not comfortable that their health information was kept confidential, and up to 8-percent of individuals may have tested without consent.

To sum up the findings, on the positive side, we have seen that routine testing may lead to gains in testing and treatment uptake. It also appears to be widely supported by

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the population of Botswana. On the negative side, concerns were raised about the quality of informed consent and confidentiality. Also, the majority of people felt they could not refuse the test. Without more careful monitoring of the process, we don't have enough definitive data on the real impacts of the policy. Monitoring will be important going forward in Botswana and elsewhere, to ensure adequate protection of human rights.

In view of the heterogeneous implementation of the policy in Botswana, and the somewhat limited data, there are still several unanswered questions. Is an opt-in or an opt-out approach to provider-initiated testing more effective in increasing treatment uptake and in ensuring protection of human rights? What type of pre-test information is adequate for informed consent, and what measures are necessary to protect individuals from violence and discrimination?

Finally, Botswana is atypical in that it's got a high GDP, a strong government commitment to combating HIV and an extensive healthcare infrastructure. I would therefore urge caution in generalizing this experience to other more resource-limited settings without an extensive evaluation of local circumstances. Thank you.

[APPLAUSE]

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CHRISTINE GRADY, R.N., PH.D.: I'd like you to join me in thanking all of the speakers for not only sharing wonderful information with us, but doing so within 10 minutes, which is really tough.

[APPLAUSE]

And then I'd like to invite any of you to come up to the microphones to ask questions or comments. We'd like to ask you to make your comments as short and concise as possible and we'll ask the speakers to respond in as concise a way as possible as well.

And if you could just introduce yourself briefly, the fellow at the front here.

PETER TIRUTI [misspelled?]: Thank you. My name is Peter Tiruti from the National AIDS Control Program, Ministry of Health in Kenya. And I just want to salute Kevin De Cock for the wonderful job he's done at WHO and the work he's also done while he was in Kenya.

I just want to say that PITC, certainly for us working in a high-prevalence setting, is not new concept. We've had it in PMTCT settings for close to seven years now, and it has helped save lives, it has helped save lives of children. I want to say that despite assurance from the honorable judge, I felt alienated that this divide between the medical fraternity and the human rights is not being bridged but it's getting

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wider. And just to say that I think we should advocate for the right to know your status as much as we are advocating the rights for access to treatment. I think it is hypocritical to advocate for universal access for treatment without advocating for universal access to knowledge of HIV status. And it's hypocritical to access the universal knowledge of HIV status without advocating for the structures that will make that happen.

We from the developing country, and speaking about Kenya, we've even gone behind PITC. We're trying to access HIV testing at the home level. And I think we will continue to do that. We will continue to make this available and to let history judge us whether that was correct or not.

[APPLAUSE]

CHERYL OVERS [misspelled?]: Hello, I'm Cheryl Overs from the Asia Pacific Network of Sex Workers, and I'd like to - my salute goes to Justice Kirby. And I just wanted to give an example in practice of something that Justice Kirby spoke about, but with reference to what Promise spoke about, which is the power imbalance between patient and medical service providers.

I recently saw with my own eyes an example of this power imbalance when I was watching police and doctors together going into the streets of Ulan Bator [misspelled?] in Mongolia

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where they arrest 17 women twice a week, take them back to the police station and test and take bloods all in one room for HIV testing. This is apparently not mandatory testing. It's provider-initiated. And it's provider-initiated because the doctor who's with the police who takes the women to the police station is called a health service provider and they initiate the testing, and I think that's an excellent example of what Justice Kirby called a weasel word. And it's masking the move towards mandatory testing.

And I noticed that all the panelists spoke about what are called in public health terms, the general population, Dr. De Cock mentioned drug users, et cetera, and as a representative of et cetera, that is sex workers, I would like to say that we're very, very concerned about provider-initiated testing, and we're very concerned about the weasel words about what a health care setting is and who a healthcare provider is and how their power is going to be exercised.

And by the way, that program in Mongolia is funded by UNFPA and the Global Fund and I agree that it's an absolute disgrace and goes against the very basis upon which the United Nations was founded.

[APPLAUSE]

DR. FLORIN DELORES GOMEZ [misspelled?]: *Buenos tardes.*
Good afternoon. You know, I am wondering why here is only 50-

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percent of people speak English. Why are not the other 50-percent have translators here? I will try to speak in English. I am Dr. Florin Delores Gomez from Cuba, but I work in Botswana. I am the head of the [inaudible] unit in Botswana. And I would like to make another figure on why I strongly recommend that the people, the other countries, do the same that we are doing in Botswana. First one was a strong political will because the president [inaudible] is also the head of the National AIDS Council in Botswana. This is the first one that we need to [inaudible]. Now there is routine HIV testing policy that was launched in 2004 in Botswana [inaudible] for the president. And then we move the first one - we move from [inaudible] to rapid testing, because people that attend the [inaudible] took around seven days in the best cases to get diagnosis, and about 20-percent never come to get the results. Then we are doing routine testings as opt-out - very clearly it's opt-out. Then at the end, we select rapid testing because people now get their results in 20 minutes or at least in two hours. It is very good to link routine testing with rapid testing. Then, we are offering the people, when people attend the health facilities, all clinics and all hospitals in Botswana, the health worker will have counselor, we have social workers, we have nurses, doctors, offer the test. It's only to offer. If the people consent the test, now

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the [inaudible] of consent in women is around 92-percent, in men is around 90-percent of people that accept. Of the people not as concerned, most of the time we suggest that they go to the counseling and get counseling to explain why it's good that the person takes the test. Then around half of the people going to the pre-test counseling after that accept to take a test.

Then we are using routine testing for people that [inaudible] will to give the example is around 50-percent or 55-percent. Second is PMTCT, 25-percent of routine testing is PMTCT and the rest is TB, rape, STIs and clinical suspicion. We think it's very good. In Botswana now in 2004, we agreed to start [inaudible] this lady. We got 42,000 testing. Now in 2006, all the [inaudible] testing we did [inaudible] 42,000 tested. [Inaudible] were estimated and we are now doing about 300,000 tests in Botswana every year. We have a population of 1.7 million. It is a very high rate for testing.

The problem is 67-percent still are women, around 33-percent are men.

WILLIAM O'LOUGHLIN: We're going to have to keep on moving. Could you sum up fairly quickly?

DR. FLORIN DELORES GOMEZ: We have to give the figures. 45-percent of people in the rape -

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WILLIAM O'LOUGHLIN: Yes, but there's other speakers behind you.

DR. FLORIN DELORES GOMEZ: Thank you. Let me just finish. Then 45-percent of the people in 2004 were positive, and now it's 20-percent. A reminder that we are [inaudible] more. Thank you for listening to me. I would like to be there to present the statistics for you.

WILLIAM O'LOUGHLIN: Thank you.

[APPLAUSE]

CHRISTINE GRADY, R.N., PH.D.: If you could hold one second, we're going to see if some of the speakers want to respond to some of the previous questions or comments.

KEVIN DE COCK, M.D.: John [inaudible]. If I could just perhaps quickly respond to the colleague who gave the examples from Mongolia. I think - you know, obviously, I think everybody would agree that that sounds like an appalling situation, but I don't see what it has to do with the WHO recommendations. I mean - things need to be done right, and that's true whether you're talking about rolling out an antiretroviral program or HIV testing or any of the things that we do in the struggle against AIDS, they've got to be done right. And that's an appalling practice that you described, and it should be condemned, but I don't quite see what it's got to do with this particular discussion.

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I think we all should accept that it is possible that implementation of PITC will have adverse consequences in some people. We have to accept that. At the same time, the current situation of the figures that I gave and others had given, lead to HIV disease, death, further transmission that could have been prevented, because testing itself does have some prevention benefit. And it's a balance.

Now, whichever side of the argument we come down on, that's fine, but if you take ownership of the adverse outcomes, and it's a question of judging - where does greater benefit lie? And based on my own experience and, I think, evidence from studies, I think it's pretty clear that diagnosing HIV and offering people antiretroviral therapy is probably the most important thing that's happened in this epidemic. You take ownership of the decisions you make, and that we all have to be prepared to do.

THE HONORABLE MICHAEL KIRBY, LL.M., A.C., C.M.G.: I would agree that the notion of ownership is the notion that the individual controls it.

[APPLAUSE]

I mean, there are two issues here. One is the issue of what is pragmatically best and what will do the best for the great majority of people, and that's a very important factor.

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But it has to also be secured in a context where we involve people in decisions that affect them.

Now, I myself, I agree with virtually everything that Kevin De Cock has said. On the comment from Kenya, I agree people have a right to know, but it has to grow out of their desire and their involvement, and it really bears out what Ruth Macklin has been saying constantly in the United States, this notion of informed consent is not a top-down thing. It's a matter of involvement and participation. Many doesn't necessary know best. It's a matter of involving people in their medical care.

And I can say from health care settings and so on that I myself sit on the nation's highest court. I write judgments about the importance of informed consent. But a few years ago, after a routine test, I was found to have a problem with a heart valve or heart blockage, and I went to a hospital only two kilometers from here and they said, you're not going anywhere, you're going under the knife. And I found what actually does happen in terms of informed consent. I suppose I could have opted out - but in fact, I just had to do what I was told. And they asked my partner, how can we can stop this man going back to work? And he said, easy, I'll take his pants.

So I was kept in the hospital. So it's a matter of involving the patient, and I think what that involves in

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different settings in the United States and in Botswana and Kenya and different societies, and Mongolia, is going to be somewhat different. But the fundamental notion has to be respected because it lies at the core of our human dignity and our right to know ourselves about ourselves.

[APPLAUSE]

CHRISTINE GRADY, R.N., M.D.: If I could take the chair's prerogative and make one comment. I've found it very fascinating in that regard, Dr. Weiser's data on comparing people who had had voluntary counseling and testing and people who had had routine testing, and a surprisingly high number in both groups who felt like they could not have refused the test.

SHERI WEISER, M.D. M.P.H.: Yeah.

CHRISTINE GRADY, R.N., M.D.: So I think one of the interesting challenges for all of us is if that's the case in the majority of people regardless of the method of testing, how do we fix that, and then find the method of testing that has the highest uptake and gets people into treatment, when they feel like they can refuse.

LOUISE BINDER [misspelled?]: My name is Louise Binder. I'm from Canada. I would like to support the comments that have been made by Promise and by Justice Kirby. And I'd like to make a few comments about my own country to give some evidence base to my position. I certainly do not want to have

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bad public health anywhere. I certainly do not want to have human rights create a situation where there's bad public health.

But with all due respect to Dr. De Cock, I see absolutely no inconsistency between protecting people's human rights and having good public health policy. In fact, I think what actually happens is that when we don't look at people's human rights, we create lazy, unimaginative, simplistic - simplistic in terms of administrative - public policy. In Canada, we each province makes its decision about what kind of testing to do. And in the province which I live, which has one of the highest rates of HIV, we do opt-in testing for everyone, including pregnant women. Some other provinces have done opt out. We have a 92-percent take-up rate and it's been going up and up and up as the medical community has become educated in how to explain this situation to women, why it's valuable to them and why it's valuable to their fetus. Other provinces, one of the opt-out testing provinces has 98-percent, but all the other opt out provinces have far less than our opt-in province, one of them as low as 60-percent.

So I don't agree that what we're really doing with opt-in is some people will be hurt. Well, nobody needs to be hurt. If we do good public policy, and we look at human rights, each individual will do the thing that will not hurt them. And I

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think that what you do is decide that some people are for the trash can and some people aren't. And I don't think anybody needs to be for the trash can in this.

[APPLAUSE]

CHRISTINE GRADY, R.N., M.D.: Okay. Go ahead. Please introduce yourself.

JEFFREY CATER [misspelled?]: Thank you. I am Jeffrey Cater from the Ministry of Health in Singapore. Could the panel recommend about the difference in the levels or thresholds in which provider initiated HIV testing should be initiated? In the U.S. CDC guidelines, it is .01-percent as the threshold. And in WHO guidelines to initiate PITC. So there's this difference.

A second question is for Dr. Branson. Has there been any ground issues in implementing the CDC guidelines? For example, in your emergency departments, I would imagine that some patients would be too sick to understand what is being offered to them, to understand what the issues are. Have there been any ground issues? Thirdly, are there any comments on mandatory testing of health care workers involved in exposure procedures? Thank you.

BERNARD BRANSON, M.D.: I can address at least some of the issues related to threshold and in particular, the difference between the U.S. threshold and the WHO threshold

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does have to do with in our perspective both the extent of disease and cost effectiveness studies showing that the benefit to individuals in terms of quality adjusted life years and the benefit from screening was clearly cost effective as other health interventions that we undertake in the United States down to a prevalence threshold of .01-percent. We recognize that this is different than the threshold recommended by the WHO.

We also, I think, have different circumstances in terms of access to treatment in the U.S. and as well as legal protections against discrimination. And so you would not necessarily advocate that every other country adopt any kind of policy like this until they have similar protections and have thought them through substantially.

With respect to the issues of doing this kind of screening, the practical issues in health care settings and whether that's emergency departments or anyplace else, we don't anticipate that every single patient will be screened immediately and that we'll have this all over with in just a year. Obviously, there are other circumstances that take precedence. So if a person is acutely ill, and they need immediate medical attention, an HIV test would not supplant the other services which they need in that circumstance.

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You asked - at least the last question with respect to health care worker exposures, and in the United States, although each of those determinations is made on a state-by-state basis rather than by a national authority, in almost every setting, testing after a health care worker exposure is voluntary. So the person who is the source of the exposure does have the option to decline an HIV test, in which case the health care worker needs to make their own decision with respect to whether or not to take prophylaxis on their own. And so we do not have in almost any circumstance a policy of mandatory testing.

And the only places that we have requirements of mandatory testing in the U.S. have to do with military service, and have to do with blood donation, tissue donation and organ donation, similar to the lists that Kevin De Cock presented.

BERNARD BRANSON, M.D.: And so we do not have, in almost any circumstance, a policy of mandatory testing. And the only places that we have requirements of mandatory testing in the US have to do with military service and have to do with blood donation, tissue donation and organ donation, similar to the list that Kevin De Cock presented.

HONORABLE MICHAEL KIRBY, LL.M., A.C., C.M.G.: Could I just say that I thought Dr. Branson's point about the different setting of the United States and the context of very strongly

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developed principles of privacy protection and legal protections and the environment in which the information is given to the patient and the security for confidentiality, that's one thing. But if you read the material from other parts of the world, and in particular from Africa, there isn't that environment. And there's gossip and there's stigma and there are no laws that give the antidote for the discrimination. So I think we've just got to be very careful extrapolating.

And I did wonder, if I can say so, Dr. Branson, whether the United States and the CDC would have taken the same measure if that graph had shown not very large black populations and Hispanic populations to introduce the CDC into those.

[Applause] I think they've been very much white populations of people who were exposed. And I must congratulate Dr. De Cock and WHO and UNAIDS, because if you look at the two, the CDC principles and the new UN and WHO principles, there is a very important and fundamental difference in the UNAIDS principles. You must get a definite and specific agreement of the person. And I think that is at the core of the fundamental notion of involving the patient and respecting their dignity.

There is a bit of a tendency in the United States, if I can say so, generally to be testers. The president, President George W. Bush has authorized no less than \$23 million to

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initiate a system of testing in schools throughout the United States of students against drugs. Now, it is really a question of whether that's a very effective way to deal with that particular problem. But there are testers out there. There are lots of testers. And it's not necessarily the best way to deal with all of these problems. And it's often motivated by all sorts of undercurrents that I won't go into in this setting.

[Applause]

KEVIN DE COCK, M.D.: Well, I think the judge is being a bit judgmental. [Laughter] [Applause] These people, they condemn people. That's how they make their money. [Laughter]

Perhaps just a couple of comments: Let me just answer perhaps on behalf of Dr. Branson that the issue in the United States of health disparities is a very, very real one. But, you know, I think the development of the CDC guidelines, and I'm grateful for the comments about the WHO guidance, the purpose of the CDC guidelines is to increase people's access to services. That's what motivated them. And I participated in some of these discussions, and know many of the people who made the decisions. And it was motivated by increasing access to lifesaving services. And public health and clinical medicine have to deliver services where those particular services are

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needed. So we need to be a bit careful about talking too much about motives.

I just want to make a comment on the issue of power imbalance, which I think is fascinating, because I think some of the problems we're dealing with, we're talking about, I think are inevitable. I mean, if you go to a health provider, yes, there's going to be a power imbalance, just as there's one if I go to a lawyer or appear before a judge or whatever the professional interaction is. And, I mean, I think Justice Kirby illustrated, by saying how awkward you felt when you had a serious medical issue, and really your decision making authority was there theoretically, but practically and emotionally probably was not. But that's what we're dealing with, and there's no way around that. And, you know, we create a lot of problems by – I hate to say this, and I know you'll disagree – we do create some of the problems by making in the medical context treating HIV different from other medical issues, because actually medically it has many of the same problems and facets that other difficult medical issues have, you know, a woman who discovers she has breast cancer, or carcinoma of the cervix or some horrible neurological disease or whatever.

Public health and human rights: Can we have both? Of course we can have both. But I think, like we can have a test

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that's sensitive and both highly specific. But we can't get away from the fact that there is a tension between them. And if that were not the case with human rights and public health, we wouldn't need things like the Siracusa Principles, which are a very useful guidance on how to deal with public health interventions that are intrusive or restrictive. If pandemic influenza should come, we will see major intrusiveness from public health with implications for human rights, as we did in the SARS epidemic. And nobody batted an eyelid, and they should have done, because I think some things were done which were pretty difficult and not really even necessary.

The lady who said I was putting people in the trash can, I find that rather pejorative. That was not the purpose of the WHO guidance. I agree. I've seen some of these data from Canada, I've heard them before, that high rates of uptake have been achieved. But I think most people's experience internationally has been that the opt-out approach – and we tried to avoid the use of those terms in our guidance – but most experience internationally has shown that the data shows that the opt out approach in most situations has actually increased uptake, as Dr. Branson showed. Let me stop there.

SHERI WEISER, M.D., M.P.H.: One comment here about definitions. In some of the literature, it seems that people use an opt-out approach to be synonymous with provider-

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initiated testing in general, and an opt-in approach to be synonymous with client-initiated testing. And I think that the way that the UNAIDS and the WHO currently defines opt in testing as being provider initiated testing, but that you need explicit informed consent from patients, hasn't been adequately studied yet. So it's my understanding that we don't have any definitive data yet on whether – or we have limited definitive data on whether an opt-out approach or an opt-in approach will be more effective at increasing treatment uptake and also in insuring the human rights protection.

BERI HULL [misspelled?]: My name is Beri Hull. I'm also with the International Community of Women Living with HIV. I'm based in Washington, DC. Thank you for this session. And I want to start by saying I am fully in support of people learning their HIV status when they are ready, willing and able. And there's a lot that goes into being prepared to receive an HIV positive diagnosis. And it's more than just having access to treatment.

I wanted to direct my comment to Bernard Branson's presentation. And he showed all these increased findings of people living with HIV or diagnoses in the United States, and of course more people being testing. So there's going to be a need for more prevention and care. But what I didn't hear, and what I know is that there's no scale-up in care and prevention

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services in the United States. And there's something wrong with that picture.

And also, you mentioned that there are protections in the United States against stigma and discrimination, and I can tell you, you know, that I take ownership of my decision to get tested in 1993, and I tested positive. And now I find myself as a person living with HIV seeking health insurance, as an individual and unable to get affordable health insurance [applause] with decent coverage. And I want to know what the U.S. is going to do to protect people who are going to test positive and be in that situation. Thank you.

[Applause]

BERNARD BRANSON, M.D.: I certainly don't intend to try to defend the entire U.S. health care system and the way it functions. However, I think I would comment that, similar to what Kevin De Cock said, in the circumstance that you point out, and individual with diabetes or with heart disease will have as much difficulty getting individual health insurance as a person with HIV disease. It's a flaw in the system. I think that our intention, certainly at CDC and working together with other agencies like HRSA, is to increase the access of care so that there is a parallel increase to the services made available to people as their testing increasing.

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There has recently been an increased commitment to the ADAP program. And I understand, similar to the need for scale-up in the developing world, that this is not going to necessarily have people standing by waiting for other people to come into the doorway. But I do feel that there is a substantial commitment to make the treatment available. That was the primary intention of these recommendations, to make sure that people were diagnosed earlier to improve their health and to give them access to lifesaving benefits.

BERI HULL: Okay. Well, please scale up, you know, those services that they need once they test positive, or test negative.

HONORABLE MICHAEL KIRBY, LL.M, A.C., C.M.G.: Could I just add that it's not only the issue of insurance. Don't let's underestimate this issue of criminal penalties and criminal prosecution, because there's a whole wave happening all around the world of legislation and laws that are going to stigmatize and penalize people. They'll get very long sentences and they'll go to jail because they know their status because provider initiated testing has informed them of that status. So we've also got to look at that.

And I'm not sure that there is a good analogy between breast cancer and influenza and things like that and HIV. HIV still is a somewhat unique thing. [Applause] And it's because

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out there, there are people who not only are testers—they want to test everything – but there are people out there who hate sex. And they hate drugs. And they're fearful of these things. And they want to make a big thing about it. And they hate people who get involved in it. And there's violence out there. And we've got to face these facts. These are the realities of AIDS.

[Applause]

CHRISTINE GRADY, R.N., Ph.D.: We have a question up at the top.

ANISH MAHAJAN, M.D.: Hi. My name is Anish Mahajan from the UCLA Program in Global Health. A quick question for Dr. De Cock: We recently performed a systematic review of stigma. And we found that it's difficult to measure. It's difficult to define and reduce. But one thing that there does seem to be some evidence about is that stigma is very thick in health care arenas in a variety of contexts around the world. And this is certainly borne out by the anecdotes we heard today, and by the data in Botswana.

So, my question is, I wonder if the WHO guidelines on PITC should state something like, the program should only be implemented when specific stigma reduction strategies are also implemented in those health care arenas. I just wondered what you thought about that.

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KEVIN DE COCK, M.D.: Thank you. I think that's an important, interesting question. And I agree with you about the nebulous, the very real but nebulous nature of stigma. I was actually going to ask Justice Kirby if he wanted to define stigma, because he opened his talk with it.

It's a very difficult concept. I think it's a very human concept, regrettably. It's not something we should be proud of. Again, I would say though it is very special in HIV. I agree with the judge. However, don't underestimate how important it is in other medical conditions: epilepsy, mental illness, even diseases that we're more familiar with, like cancer or tuberculosis. The Justice Edwin Cameron from South Africa has written a very, I think a very important book where he talks a lot about stigma. And he emphasized the importance of the internal nature of stigma for many individuals, a sort of sense of shame or self-blame that goes with it. And I agree it's difficult to measure. It's difficult to define. It's very pervasive.

So, actually, I don't think we have any strategies for it. My own bias is that one thing that does reduce – and it's a bias. This is opinion rather than data. But in my opinion, and based on my own observations, I think familiarity is something that reduces stigma. And the Minister of Health from Botswana certainly feels that very strongly. And I've heard

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her argue passionately that in Botswana stigma has reduced as a result of increased knowledge of serious stages nationally and greatly increased uptick of antiretroviral therapy. Now, that's her opinion.

So I think your suggestion is interesting but difficult to actually implement. But I'd be interested to hear what the judge says about defining stigma.

HONORABLE MICHAEL KIRBY, LL.M, A.C., C.M.G.: Well, we could be here for a long while defining stigma. I think it's a bit like obscenity. As a judge of the Supreme Court of the United States said, "You know it when you see it." And certainly there is a lot of stigma about HIV. And Edwin Cameron also says, in witness to AIDS, he gives stories about the violence that occurs.

But I do agree with Kevin De Cock. I think a big way in Australia we fought the huge stigma against Asian-Australians was when we got to know them as neighbors, as friends, as shopkeepers. And I think that really helped us. And now we've gone on from there, from white Australia. And similarly with sexuality: One of the reasons I, as a constitutional office holder and justice of the high court, am completely open that I'm a homosexual man is because nothing will even change until people know that that is what I am, and

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that people can get over it. They can take an aspirin, and they can go to sleep, and they'll feel better the next day.

[Applause]

So, I do agree that that is a way that we can confront it. I do agree that as it becomes more common and known, there will be less stigma. But there is this present period, and we can't ignore the stigma. I agree with the questioner. It's got to go in tandem. You've got to have anti-stigma policies as well as testing policies.

SHERI WEISER, M.D., M.P.H.: I just wanted to add, in terms of the data from Botswana related to stigma, in our study we actually did find a decrease in stigmatizing attitudes compared to a very similar survey using a similar measure before the role of antiretroviral therapy. And we also found that perceived access to therapy was the strongest correlate of not having stigmatizing attitudes. So there does seem to be a link between access to treatment and reduction in stigma.

On the other hand, even with this widespread availability of treatment and increased uptake of testing, we still found that a majority of participants still held at least one stigmatizing attitude. It was something like 50-percent. And even a higher proportion anticipated that if they were to test positive for HIV and disclose their status to others, they would be the target of negative social consequences. So I

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think a key point here is that while treatment access may be necessary to reduce stigma, it's likely not sufficient, and other measures need to be occurring simultaneously.

KEVIN DE COCK, M.D.: Can I just make a - I had a quick comment. I don't think we can have policies against stigma. I think we can have policies against discrimination. But stigma: How do you have policies against stigma? It's this nebulous-

HONORABLE MICHAEL KIRBY, LL.M, A.C., C.M.G.: You can have a policy of education and information and soap operas on television and all the other things.

PROMISE MTHEMBU: Can I-

WILLIAM O'LAUGHLIN: And I'm sorry to continue this, but there's just one thing we need to make very clear. We haven't discussed in this room today the epidemic in Asia. And it's very much an epidemic of men who have sex with men, gay men, injecting drug users and sex workers. And consequently, the framework of the epidemic in this region is a highly stigmatized context which has to take into account those analyses, when you look at a public health response. And therefore, there have been some very strong concerns raised about the appropriateness of this policy in this region for those very reasons, as distinct to what might be appropriate in a setting like Africa or in a more developed context.

[Applause]

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PROMISE MTHEMBU: I wanted to talk on stigma, that I have a problem with the term, the stigma designation, the horrible twins. I tend to use the language of breaches and abuses, because if you use those terms you are talking to specific human rights abuses and breaches. Then you are able to hold whoever accountable. Stigma designation are popular in governments because in my humble opinion it takes the responsibility away from government, the responsibility to deliver rights, and it shifts it back to the community. So if you say stigma, whose responsibility, who is to account? So I tend not to like to use the language of stigma designation.

And I love governments, but I'm concerned with the case of Botswana, because we don't have people with HIV from Botswana to say what they feel and live in Botswana. You know, we get the viewpoint of the Minister of Health of Botswana. And I'm not sure what the [inaudible] will feel if I say that people of Botswana go for an HIV test because they feel that there isn't anything that they can do. They have to take an HIV test if it's affected them. And I'm not sure whether you regard that as a country where there is a culture of human rights. And why would the Minister of Botswana say that HIV testing is reducing stigma and not to people who live in Botswana communities who are probably feeling stigma?

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So I'd be quite sort of skeptical to use Botswana as the example, particularly because there are no people living with HIV from Botswana here to tell us exactly what is happening to them. Thanks.

[Applause]

CHRISTINE GRADY, R.N., Ph.D.: We have three people who have been standing at the microphone patiently, and we're actually after four, so if you can each make your questions or comments very short, we'll finish with-

MALE SPEAKER: In the parlance of Mister Justice Kirby, I would beg the panel's discretion and redress an issue that was raised the very beginning by the lady from the commercial sex workers of Asia specific region, if I may. I think we lost a little bit of the thread when we discussed who owned ownership of the policemen doing this informed kind of consent of provider induced testing. Think about the story. A policeman and a physician are working together. And the physician is doing the begging of the police. He has dual loyalties, or he has only one loyalty, that to his boss and maybe not to the patient.

Think, now, in a hospital environment, where we want to have testing with confidentiality. And it's not too outlandish, the story of the policeman, because we have in civilized society the story of the third-party payers, the

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insurance companies. And we have the health care provider, mainly the physician, caught between a loyalty to the patient and a loyalty to his paymaster, which is the insurance company.

And so I think, while it was correct initially to discuss who owned ownership to the WHO policy or not, the issue becomes the practical part of it when you're actually where the rubber meets the road, and a health care worker has dual loyalties, and those loyalties become too lopsided. And we don't have discretion, we don't have confidentiality, we don't have privacy. We just have a patient getting screwed. Thank you very much.

HONORABLE MICHAEL KIRBY, LL.M, A.C., C.M.G.: Could I say that I agree? And I hope nothing I said minimized what Cheryl Overs had indicated. I've been intimately involved with Cheryl, over 20 years [laughter], and she's been a great fighter for commercial sex workers.

But there is a fundamental problem with informed consent. And that is that nobody can convey from a mind to the patient in the available short time all the knowledge and information and values and experience and so on. The most you can accept is the great principle of medical ethics and international human rights law, that it's the patient who matters and it's their dignity and their right. And everything that we do has to be framed around that fundamental principle.

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MALE SPEAKER: I had no question about what you said or Kevin had said. What I wanted to do was put in the more humanistic prospect that we can have whatever policies promulgated by whatever governments, whatever bodies. But somebody—people will have to put them into practice. And there is a potential weak spot. That's all I want to say. Thank you.

CHRISTINE GRADY, R.N., Ph.D.: Maura.

MAURA ELARIPE [misspelled?]: I'm Maura Elaripe from the [inaudible] organization in Papua, New Guinea. And I'd like to make a point here on the treatment of [inaudible]. In my country, I see this being very problematic, because we don't have treatment services. The rollout is so slow, we don't have care and support programs in place. So there are not many in place. And to have this is like another building already because my organization has a number of positive people coming in who don't know, are not receiving proper counseling and being tested. It's a big burden to us. I see this as another burden to the already big problem we have. Thank you.

LAURA ARMAS [misspelled?]: Laura Armas, Dallas, Texas. It's not its own country. I'm sorry, USA. I just want to make a comment about stigma. I think it's more than a stigma, is the way that the medical community has talked about it. We keep talking about risk factors, risk factors, risk factors. I

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cannot believe so many thousands of delegates flew in the area of MDRTB, took the risky behavior of being in an airplane for 15 hours, coming here and being so, you know, risk prone, knowing all you know about TB and how it gets contracted.

But I think I really do agree that as long as we keep the dehumanizing HIV, which is the Human Immunodeficiency Virus, we're not going to get anywhere. We need to start talking about sexual behaviors instead of risky behaviors. We need to talk about psychological problems behind injection drug use or psychosocial, I should say, problems behind injection drug use rather than risky behaviors, because I have not met a single patient of mine who engages in unprotected sex or in injection drug use that did not do it for either love or because of some psychosocial issue. And we really need to start looking, not at the patient in their risk category, because we're all at risk of something.

And I do agree with Mr. De Cock in relationship that it should be characterized as any other disease. There is a stigma here. We just had the experience in Texas with the HPV vaccine, and the activist groups really senselessly refusing to take up this vaccine for all girls because this is a sexually transmitted virus. It is just this sexually transmitted that puts that stigma into the medical community and the society. And I think we have so much to learn from our colleagues who

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are medical anthropologists, who do great qualitative research in helping us overcome stigma, so we can move forward and start creating a new language for a virus.

I'm 100-percent for routine testing. I'm a women's specialist. But I am very concerned about what – and that is a question for the panel. That is my question. What are we going to do to get more men into access to testing and treatment?

And just one final comment: The health care system in the United States is not as perfect. As a matter of fact, we don't have a universal health care system in the United States. We don't. I mean, it's just fragmented. And the ADAP programs have done a great job. But we continue to be flat funded. And yet access becomes an issue. Hopefully, with universal testing, more awareness from more powerful groups will come, because I don't think that HIV distinguishes into any social, economical or political strata. And familiarity is going to bring us to our knees. In familiarity, I mean when it knocks at our doors with our children, our sisters or our brothers. Thank you.

[Applause]

WILLIAM O'LAUGHLIN: We do need to finish. We've gone over time. But I think people will understand that this is one

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of those topics that there are many juicy aspects to. And I think today we've covered a lot of the key areas.

Certainly, in the Asia region, we're about to commence a process at country level of looking at how these WHO UN guidelines are best implemented according to the context of each country. And hopefully, there will be a similar level of vigorous discussion and analysis going on at that level.

I'd like to thank again each of the presenters for this afternoon, on your behalf, and thank you all for coming.

Goodbye.

[Applause]

[END RECORDING]