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**Putting HIV Testing to the Test: Progress, Gaps, and
Opportunities
Kaiser Family Foundation
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JONATHAN COHEN: Welcome, ladies and gentlemen, to this session. Is this on? Yes. Welcome to this session: Putting HIV Testing to the Test: Progress, Gaps and Opportunities. My name is Jonathan Cohen. I'm with the Open Society Foundations and I will be co-chairing this session, along with Susan Timberlake, who is the senior human rights and law advisor at the UNAIDS Secretariat in Geneva.

I'm going to begin by introducing our panelists, or our discussants, today, after which Susan will give some brief framing remarks from the session. We'll then have a presentation by one of the discussants and then engage in a conversation with the entire panel.

Both Susan and I encourage the discussants to respond to each other's points and to generate a discussion amongst ourselves about this very controversial and challenging issue, and about 45 minutes to an hour into the session, we'll open it up for audience participation so that we can get a discussion going with the room.

We're extremely lucky to be having this discussion in the company of our four discussants, Paul Wekesa, Morolake Odetoyinbo, Katerina Jiresova, and Mark Heywood.

I will start on the far right. Paul Wekesa is, I believe, the one medical doctor on the panel. Paul is the director of services at Liverpool VCT, Liverpool Voluntary

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Counseling and Testing in his native Kenya. He has a wide range of experience as an implementer of HIV testing programs, a variety of different kinds of HIV testing programs.

Liverpool VCT has been, I think, very much on the front lines of recent efforts to expand provider-initiated testing and counseling in a generalized HIV epidemic, and he will be providing us with his experience as an implementer.

Morolake Odetoyinbo, well known to many of you here as a very eloquent, brave, outspoken AIDS activist and living with HIV from Nigeria. Morolake is the project director of positive action for treatment activist. In addition to her AIDS activism, she is a writer. She is a TV producer. She is a presenter with many years of experience in journalism.

She is the alternate board member representing communities living with HIV for the global fund to fight AIDS, TB, and malaria, and she brings to this panel a deep community perspective and particularly a perspective of women's human rights to the issue of HIV testing. So, welcome to Morolake.

Our third discussant today is Katerina Jiresova from the Slovak Republic. Katerina is an expert in particular in the human rights of marginalized populations, people who use drugs and sex workers in central and eastern Europe.

She comes from Slovakia, as I mentioned before. She's been working in this field for over 15 years, directs the NGO Odysseus, has a perspective on access, or in some cases, lack of

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access, to HIV testing amongst the most marginalized in society in concentrated epidemics, which is a particularly important and often overlooked perspective, and we're very lucky to have her here, particularly because of where this conference is and because so much of the discourse on HIV testing is about generalized HIV epidemic. So, thanks, Katerina, for being here.

And finally, Mark Heywood, the founding director of section 27 in his native South Africa, the head of the former AIDS Law project, a very well-known, prominent AIDS activist from South Africa, a global leader in the use of human rights and legal strategies to advance rights-based responses to HIV, the chair of the UNAIDS reference group on HIV and human rights, and truly a star in the galaxy, if I can call it that, that is the global AIDS response.

We are extremely fortunate that Mark Heywood is speaking on this panel, not only because of his vast experience and perspective but because he can bring extremely recent and important information about the rollout of HIV testing in South Africa, which is an issue, I think, much on the lines of delegates to this conference, and can comment on that from a health and human rights perspective.

So, please join me in giving a generous welcome to our panelists. [Applause]

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SUSAN TIMBERLAKE: Thank you, thank you. Can you hear me? This is great that you're here. I think we're in an incredible time in the history of the HIV response and we're at an incredible time to look at HIV testing. There's a long history of HIV testing in this response, and it's in many ways the testing has shaped the response.

It's because we have a cheap and easy test, which is becoming cheaper and easier, that we've had the kind of response, both good and bad, that we've had to HIV for many years. And in fact, if we had such a cheap and easy test for other health conditions, it would probably also change the nature of the responses to those health conditions.

Now, you all know the long history of VCT, voluntary counseling and testing, which is now known as client-initiated testing. We've moved from that to what we call provider-initiated testing and counseling in health services, and now we're moving beyond that to something that is state initiated or community initiated, which is mass testing in some form, door to door testing, group testing, crowd testing, outside of any sort of health-related facility.

All this has meant that there's both promise and peril with regard to HIV testing. The promise, of course, is knowing one's health status, which is a fundamental part of human rights and the right to health. In the early days it was the gateway to what we called positive living. There was no

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treatment but there were still good steps you could take that would help you keep healthy and strong as you move forward in your infection.

Now it's the gateway to treatment. We're hearing at this conference that it's the gateway to prevention. Treatment and prevention are collapsing. And of course, as we tried to attain goals such as universal access to HIV prevention, treatment, care and support, and to the millennium development goal six to roll back and halt the HIV epidemic, there is incredible political pressure, as well as health imperative, to increase testing.

The problem is is that there are a lot of negative outcomes. Testing has been conducted in so many various and abusive ways that they've had the opposite effect of the beneficial outcomes I've just named, and some of the forms that this abuse has taken, you know them well: Hidden testing where someone is not even informed that they're being tested and they're not informed about their status; coercive testing where testing has to be done to achieve something or to avoid something; testing leading to incredible disclosure and lack of confidentiality, resulting in people's lives coming apart in terms of loss of jobs, being abandoned, being thrown out of schools; testing leading to forced sterilization, forced abortions for women.

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And these sorts of outcomes are in fact, rather than linking people to beneficial health outcomes and to their human rights being satisfied, result in their lives being destroyed in many ways and every disincentive to stay in a healthcare system that should be providing them with a greater access to treatment.

So, I'll stop there. I tried to set some context of what we want to discuss today, and there are many strong feelings about testing, and I hope that this session will bring out some of those strong feelings and the controversies that are involved. And with that, Mark, I'd like to turn it over to you, please.

JONATHAN COHEN: Can we have Mark's presentation?

MARK HEYWOOD: Good afternoon, everybody. Can you hear me properly?

JONATHAN COHEN: A little closer.

MARK HEYWOOD: Thank you. I think that my task for this afternoon is to try to provide a case study that looks at the South African experience of HIV testing over the last two decades really, and tries to use the South African experience to initiate a discussion about how we should approach these questions in 2010 and beyond.

But I think I have to say at the outset that I'm very conscious of the differences and the different approaches that

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are still relevant to HIV testing across the globe. There is not one size that will fit all.

Katerina's experience in Eastern Europe must be very different from my experience in South Africa, but although there's not one approach that can fit all, I would try to argue that there are a set of principles and that those principles are rooted in human rights that have to be applied and have to be seen to be applied and observed in relation to every approach that we take to HIV testing.

So, let me tell you a little bit about South Africa, and hopefully from South Africa we can have this discussion about Eastern Europe, about Eastern Africa, or about China and about HIV testing all over the world.

Essentially what I'm going to try to do for you is just talk a little bit about the early experience of HIV testing, both internationally and in South Africa.

But having described it as the early experience in this slide, I wouldn't want you to suggest or to think that the horror stories associated with HIV testing are horror stories that belong in the 1980s and the 1990s and that stopped because today in the 2000s we have a progressive understanding of HIV testing that has eliminated all abuse and all discrimination from the conduct of HIV testing.

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Then I want to talk a little bit about how these horror stories helped us to understand the need to establish a legal and human rights framework for HIV testing in the early 1990s.

And then in the way that has been hinted at by Susan Timberlake, the question is, given the advent of treatment, now given the advent of our understandings of treatments, its prevention, and so on and so on, does the change in the risk/benefit equation around HIV testing necessitate create a different rationale for a different approach to HIV testing, an approach that is perhaps more paternalistic, more medical, that says, well, you may not want HIV testing but we know it's in your benefit, so the power shifts from the person to the provider.

Is that type of approach justified? And finally, just to mention, the shifting sands of HIV testing, from what we might call non-voluntary testing to voluntary counseling and testing to provider-initiated testing and counseling and to what we know in South Africa call HIV counseling and testing—you notice that the V is gone, but I'll come back to whether the V has really gone or not.

Now, I won't labor these points, but we all know here that the early experience of HIV testing was one where frequently we saw non-voluntary HIV testing of so-called risk groups. Whether they were risk groups or not was not necessarily based in science. It was often based in prejudice.

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It was often about testing of migrants, testing of sex workers, testing of prisoners, testing of whatever, but traditions and policies and approaches around non-voluntary testing. We saw frequently HIV testing without counseling, sometimes without knowledge, often leading to breeches of privacy and confidentiality.

There isn't time to give the examples of these in South Africa, but they are familiar, I believe, to all of us in this room. And then we saw HIV testing, which is always intended as a beneficial intervention, leading to many people to negative experiences, to violations of dignity, to violations of basic human rights, such as access to medical services, access to education, access to financial services, violations of dignity, violations of privacy, and so on and so on. So, something that is intended to help becoming something that actually causes a great deal of harm.

As a result of this, from the early 1990s we began to work to establish a human rights framework around HIV testing and to base that framework as far as possible in law.

You'll see in 1998n for example, the UNAIDS issued its international guidelines on HIV and human rights, which talks a little bit about HIV testing, but the principles, the three cardinal principles that we established were the principles of voluntariness for HIV testing, the guarantee of confidentiality as a way of protecting a person's privacy, and the principle

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that an HIV test should take place with informed consent. And we tried to define informed consent.

Certainly in South Africa the definition of informed consent that we worked with was that you could not obtain a person's informed consent without pre-test counseling, because pre-test counseling made it possible for an individual to elect to say yes or to say no, based upon the consideration of the possible risks and possible advantages that would come from HIV testing.

And each of these human rights principles, because they're related to dignity, they're related to autonomy, they're related to privacy, have been, to a large degree, established in law, certainly established in law in many parts of the world. Whether they've been established in law in Eastern Europe or Asia or China is perhaps a different question that we will come to in the discussion.

But as I've said, once treatment started to become available on a large scale across the world, from the middle of the 2000-something that we as human rights activists forced for, we began to hear voices, including voices from people who are known as advocates of human rights who started to suggest that because of access to treatment we should look at HIV testing differently.

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For example, my colleague Justice Edwin Cameron, known to all of us, a person living with HIV, a judge, began to take quite a different approach to HIV testing.

Justice Cameron, for example, began to say that he believed that pre-test counseling can be a deterrent to a person agreeing to have an HIV test, that pre-test counseling can be part of a process of self-stigmatization, and that pre-test counseling can have the opposite effect because it can lead to a person taking a decision which is actually against their best interest.

So, we started a series of discussions. We talked about should there be routine testing or routine offer of testing. They looked similar, but they're fundamentally different.

We said should there be opt in or opt out testing. In Southern Africa the Botswana government was the first government to introduce a policy of opt-out testing, but there's a fundamental difference between the person who decides yes, I want to test for HIV and a person who says, you will be tested unless you say that I don't want to be tested for HIV.

And there's a difference in outcomes as well. And then we began to question also the extent of counseling. Should we really put so much emphasis on pre-test counseling or should we rather elect for post-test counseling.

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So, those were the debates that we began to open up, and those were the debates that began to rage two or three or four years ago when the World Health Organization began to move to what was called provider-initiated testing and counseling.

And to some degree or another, those are the debates that continue to face us today in different parts of the world. And these were the debates that we had in South Africa. But I don't have time now to talk about the detail of the debates we had because I want to present to you and perhaps allow you to think and make your mind up for yourselves South Africa's latest initiative, which is an initiative that has begun to start a massive, I believe, globally unprecedented campaign to test people for HIV.

A voluntary counseling and testing campaign that aims to test 15 million people— that is about 30-percent of our population in South Africa— within the next 12 months, between April 2010 and June 2011.

And to conduct the HIV counseling and testing campaign, by encouraging voluntary take-up of available testing at health facilities and by increasing the accessibility of those facilities, by introducing a policy of routinely offering HIV testing to people in in-and-out patient facilities to all people who present with TB, to all people who present at anti-natal clinic, or people who present for sexually transmitted infections, and also linking HIV testing to care, treatment and

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other healthcare services, i.e. using the promotion of HIV testing not just for the HIV test but allowing HIV testing to allow people to test for diabetes, to allow people to test for tuberculosis, linking various other tests sort of thing, and this is the campaign that has started.

The rationale for this new policy in South Africa can very briefly be summed up as followed: There has been in our country a significant increase in VCT. A few years ago the only people who tested for HIV were people who were forced to test for HIV because they needed to take out life insurance.

But with the advent of treatment we have seen the numbers of people voluntarily testing for HIV double and quadruple, but it was still a minority of people. We were still seeing, and we still see today, that people who present for treatment are only discovering their HIV status at the point when their CD4 counts are often 50 or 60 or 70 or 80, when they're very, very sick, when they have held off from diagnosis of HIV for as long as possible.

The rationale was also the possible benefits of knowledge of HIV status for HIV prevention and further rationale was to strengthen health systems, that we could use HIV testing and the demand for health systems that would come from mass based HIV testing to kick start the health system, to force the health system to develop the capacity that would be required to meet this particular need.

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What has the experience been so far? This campaign was launched on April the 24th, 2010. It was the campaign where the president of South Africa tested publicly for HIV, the minister, the premiers of the different provinces, the general secretary of the trade union, the leaders of the churches, civil society leaders, et cetera, et cetera.

The positives are, so far, that a mass HIV counseling and testing campaign has helped to establish an infrastructure, a new health infrastructure, because it is needed to drive the campaign. At a national and provincial level, for example, there have been attempts to set up what we call nerve centers; centers within the department of health that monitor, that establish what needs are being met, what needs are not being met, that try to move resources from one place to another place, and so on.

It's forced the implementation of policies that we've pussyfooted around for two or three years, including nurse initiation of antiretroviral treatment, including counselor, community healthcare worker based HIV testing. And so far the official statistics, although I have to say that I have some skepticism about these statistics, but they were announced by our minister of health a few days ago, so you have to believe them.

The official statistics are that from April until July of this year, one million people have been voluntarily tested

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for HIV as a result of this campaign, and that 70,000 more people have been fed into access to antiretroviral treatment as a result of the campaign.

Now, that is a significant fill-up and a significant increase in the numbers. But not because I am a spoiler, not because I want to pour water on a campaign that personally I support, but I think it's important that we balance the positives with the negatives, that we constantly monitor these types of campaigns.

Because even though we are talking about large numbers, the large numbers are composed of many, many individuals, and certainly in South Africa our constitution gives us a duty or provides us a duty to look after every single individual, to take every single individual seriously, to respect their rights, to protect their dignity.

So, what have been the downsides so far? The downsides are that from a human rights perspective you can say that there is no monitoring at all of what we might call adverse events, with the exception of some civil society organizations, such as the treatment action campaign.

There's no system to monitor whether a person who is diagnosed with HIV then suffers discrimination, whether a person suffers violence, whether a person gains access to treatment. Generally there's poor monitoring of HIV testing, monitoring and evaluation of HIV testing and its outcomes.

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Research shows us that there is very poor quality of HIV counseling and testing at facilities across the board and that there are multiple breeches of HIV testing protocols in the implementation of provision of HIV testing.

We are seeing some disconnect between HIV testing and whether a person gains access to treatment. And of course there are major budgetary issues about this type of campaign, which in South Africa are demonstrated in the total lack of funding for a mass communication campaign to promote HIV testing, which I would argue is an absolute essential to make the population understand what HIV testing is about and to make it possible for people to determine, prior to entry or entering a health facility, whether they elect for an HIV test or not.

There are also some experiences that are specific to violations of human rights, and I've just picked two here, and I have to stress that these are anecdotal to some extent and that the source is an assessment that has been carried out by the treatment action campaign of the implementation of this campaign in six health districts in South Africa, but nonetheless, these are issues that we have to take seriously, and I draw out to. O

There is some evidence of coercive HIV testing. Because of a lack of proper communication to healthcare workers, some people are being corralled into HIV testing. Some people are

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being told that if they don't test for HIV they cannot have access to other healthcare services.

These may be examples that are few in number, but if they are few in number that doesn't mean that they should not be taken seriously. We don't know whether they are few in number or whether they are large in number, but they are happening.

We also have evidence in South Africa of people who are not South African citizens being denied access to HIV testing and being denied access to treatment. In South Africa we have four million refugees from many other parts of Africa with a lot of prejudice about those refugees, with denial of access to services. So these are two of the issues that we've identified that have to be ironed out if we're to make progress on this.

So, in conclusion, I want to really just not present you with a particular viewpoint but present us with a framework and present us with an argument about what we need to do if this type of campaign is to be justified.

I would argue that HIV counseling and testing on a mass scale in a country like South Africa with 30-percent antenatal HIV prevalence, with incidence of 1,000 new HIV infections a day, with low general knowledge of HIV status and with a serious treatment program, that massed based HIV testing is justifiable and that it is necessary.

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However, the end of the intention of massed based HIV testing is to provide people with access to treatment and access to other healthcare services. If that intention is not being met, i.e. if people are not getting access to lifesaving services, if people are continuing to experience stigma and discrimination, then the means cannot be justified and the means have to be reconsidered.

In that regard, it is absolutely essential that we put in place better systems for monitoring and evaluation, better systems for mass communication that aims to create health-seeking behavior through HIV testing, and what I haven't put in here which I should've put in here as a human rights activist is better systems for monitoring and protecting the human rights and dignity of all people who seek HIV testing.

So, I hope that that gives us food for thought. Thank you very much for your attention. Thank you. [Applause]

JONATHAN COHEN: Thank you very much, Mark. And we're very lucky because two of our discussants— Paul and Morolake— have also had a chance to observe the rollout of HIV testing campaigns in their respective countries, and we're going to ask them, I think, to comment on whether they see similarities and differences and their experience in Kenya and Nigeria to what they just heard from Mark.

While they're thinking about their answer to that question, I think one thing that I would highlight is the last

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slide that Mark put up where he said that essentially if the ends, if the purpose of testing is not being met, i.e. to have it be a gateway into a range of health services, then the means, which is the mass testing campaign, cannot be justified.

And that raises a very important empirical question, which is whether in the other countries represented on this panel testing is in fact functioning as a gateway to a range of services or whether it is operating more as kind of an end in itself. So, I wonder if Paul and Morolake if when you're answering if you could maybe reflect on that point as well, and then we'll have an Eastern European perspective.

PAUL WEKESA: Alright, so, I would give the perspective of Kenya, and in terms of from Mark's presentation and what I could already pick out, similarities, I think on the overall there has been a shift in paradigm as well in the testing program in Kenya, you know, from even currently the previous what was HIV counseling and testing is really at a more testing and counseling paradigm, which means that a lot more emphasis on what happens post-test as opposed to pre-test.

But I'll also give certain other aspects. For example, with that shift in paradigm, it has meant broadening of options for consent, for example, but it's not from the previous return consent to other forms of consent, including verbal.

It has meant pre-text counseling is now a lot more, it's a simpler process than before, including even moving

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towards general information as opposed to a counseling session and having that as a group as opposed to individual. And I could take it farther also to include what happens post test.

Certain aspects have been maintained, like providing post-test counseling individually, but the broader perspective beyond the test towards what other services are available, we have some success but a lot of major challenges because as from the beginning, the health system has not been strong enough to even manage the current burden, and so this has been an addition of sort of an additional burden to the health system, and it has to get to a point where it's able to absorb it just in brief.

JONATHAN COHEN: Can I just ask how, I mean, if you would, before we go to Morolake, to comment on the point that I raised earlier, which is what Mark referred to as the disconnect between testing and treatment. You said that the paradigm shift has meant greater focus on what happens after testing. Does that mean that in general people who are tested are referred to prevention and treatment services?

PAUL WEKESA: In general, yes, referral happens. The thing is that we are not able to confidentially talk about uptake of referral based on the various testing entry points, because we have both client initiative and provider initiative and testing also outside the health facility. In a health facility you may be able to trace the entire from testing to

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treatment, but if testing happens in the community setting, there is no mechanism to actually be able to verify uptick of referral.

MOROLAKE ODETOYINBO: Thank you. If we're talking about testing we have to ask ourselves really where are we coming from and what messages are we sending, and there was a slide Mark had. I remember when we just started hearing about HIV testing. We used to hear VCT, and then we insisted, no, there must be another C.

So, not just voluntary counseling and testing; must be voluntary and confidential counseling and testing, and the slogan, that was VCCT. A few years ago, I'm sorry, with the advent of PEPFAR came VCT went out of the window and it was HCT, HIV counseling and testing.

And as we focused more, there was [inaudible] provider-initiated testing, and the slogan now is opt-out, opt-in, opt-out. The question is exactly what message are we passing and why are we testing. Now, I live in a country where in our project it's almost impossible to get testing services.

The reality is programs are being scaled. There's no scale-up in program, no scale-up in treatment. So as long as there's no scale-up in treatment and you're trying to rush on services, what this means is you will not encourage people to get tested. So the first thing we are seeing is we are not able to access treatment testing like we used to access them.

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There was the myth that people did not want to get tested, that people were afraid of getting tested. Well, then that really was a myth, because we had testing programs at the bust stops, and you'd see queues of people at the bus stop and you are wondering, is something being shared? What's the gift? Is there a prize or something?

But people were actually queuing up in bus stops to get the HIV test, and they are doing it because the test was there, because it was free, because it was anonymous, but most importantly because you could get your results right there and then. And you could walk away and that was your business.

So people were getting tested. Right now we can't even access testing services. We're working in primary health centers with pregnant women, and it's sad to see that the pregnant women whom we all scream about as we talk about prevention, [inaudible] access testing services. You have programs where testing is being rationed.

Once upon a time if you were going to have a program, you'd be told we need to have at least 270 people who will be tested. That was the target. 270 per testing van, the move out testing vans. The last one is AIDS candlelight memorial. There were two counselors who came in these vans, and each of them had a target of 20 people.

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So 40 people was the target they had, because if you test and people are positive, you must refer them to services, and services are being scaled down.

So, that's the reality, at least in my own part of the world, the reality around HIV testing. And once more we're seeing we are going back to the old days where HIV testing is being reserved for people with TB, injecting drug users, sex workers, long-distance drivers, you know, the people we have always labeled as high risk, which we know that if we focus testing only on this group of people, we won't get the general population tested because you've already stigmatized the test itself. That's what we see. That's where we're [inaudible] into right now, and that frankly is worrisome.

SUSAN TIMBERLAKE: Okay. I think you both, Mark, Paul, and Morolake have opened up a lot of issues, and we need to get back to those issues, and they're issues that are rising in the context of a generalized epidemic where they're caused to normalize HIV, normalize HIV testing, explore lots of different modes of testing that will result in different uptake, try to make the connections on a mass scale.

But before we get into those, I'd like to turn to a very different situation that Katerina can talk about, and that is the situation in Slovakia, where there is concentrated and low level epidemic and a completely different degree of social mobilization around testing and a completely different degree

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of understanding about a lot of HIV issues among healthcare workers, government officials, police, and the general community.

Katerina, can you tell us a little bit about the experience in Slovakia.

KATERINA JIRESOVA: Yes, sure. Can you hear me? Okay. So, the issue is like when you have a generalized epidemic, it's kind of like normalized topic. Still there is a stigma, there is a human right violation, but it's nothing which people are used to speak about or at least heard ever about.

When you are coming from a country like Slovakia where there is registered 300 people since 1985, so it's almost like, what? Then you are just facing the issue. The people are not going tested for a couple of reasons. One of them is that you don't think you are at risk.

We are over and over ensured that our country is almost free of HIV and somehow we are the miracle in the central of the Europe because the HIV is going just around us. I don't know how we did it but maybe we can sell it out. And the second problem is that the place to go for testing are very high threshold. So, you have to know where you go.

You have to get there in between their two hours, and you have to open yourself about why you want to go for a test because usually they ask you, so, did you have any risky

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practice? Why do you want to go for a test? And you have to kind of make a coming out.

If you want to do a test you have also option to visit your general practitioner. That usually is the same person who is treating your mother or your husband, and it's like the people are not very much trusting that the information will be close in the medical room.

So, in fact we have a lot of numbers of people tested a year, but it's a numbers of women who are pregnant, and it's a number of people who undergo surgery. We are trying as an organization to open up a community testing, but this is kind of against the law in regard of the healthcare provision.

So we are trying to advocate for this, and what I found out when I was looking for international support is there is existing community testing in other parts of Europe, but it's not community testing as I do understand. There always have to be many times a doctor, and at many places it has to be a stationary.

So it's a building where you have a special provision, and that's also which is called community testing. For me the community testing as I imagine is to come to people, to come with van, to be there on site, like this bus stop. This is a great example, so people can do it right now, get a result, and get a support in both of the cases, because it's very emotionally strong situation.

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JONATHAN COHEN: One of the things that's so striking to me, particularly listening to Morolake and Katerina is that in all of this debate about mass HIV testing and should we be streamlining testing and more and more testing, one perspective that seems to be left out is that at least in certain contexts there are people who actually want an HIV test who can't get one.

I mean Morolake describes a scale back in HIV testing, a way from a situation where it was really being rolled out to a situation where it's now being scaled back to at-risk populations.

Katerina, you're describing a situation where there are community-based organizations that want to be engaging in HIV testing with populations that they have a relationship of trust with, but they're not able to do that because it's restrictive perhaps to government health centers.

So, I guess I wanted to give the other two panelists a chance to comment on the access issue as well, because clearly when it comes to human rights and HIV testing, one of the cardinal rights must be access.

There's not even a conversation to have about quality, or the way in which testing is done, unless people who want to know their status and frankly have a right to know their status can know it. Paul and Mark, do you have any comments on the access issues in Kenya and South Africa.

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PAUL WEKESA: All right, so I'll go first. Thanks. In Kenya we still have access issues, and I think that is why the ministry of health has adopted various approaches to testing, to sort of open it up, because we were coming from a point where it was only available in VCT sites, which were not many and were not accessible all across the country.

But our situation right now is that there are various approaches that someone can get to get an HIV test, including mobile testing, including home-based testing, including provider initiated testing in health facilities, including walk places as well.

So, various approaches. And it is interesting what was said by Morolake about the reason for testing. I think one of the findings from the last AIDS indicator survey in Kenya showed that actually the reason why a lot of people are not taking up the test where it was available was the low perception of risk, meaning they do not see themselves as at risk.

But what the findings were as well was that a lot of those who were HIV positive actually did not know they were HIV positive, up to 80-percent, which was quite striking. But beyond that, I think the planning for mass access to testing has not really been done in tandem with access to treatment.

So, planning has been sort of disparate so that a lot of planning goes on in terms of modalities for increased access

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to the testing, but no joint planning, or very minimal joint planning in terms of access to testing as well as access to treatment. What happens after, a lot more people come out who are HIV positive.

MARK HEYWOOD: Yes, just following on from that, I think the question is what does access actually mean. You can have very wide geographical access, like we do in South Africa now where most people can access an HIV test fairly close to them, but even in the context of easy geographical access, population access you can find that there are particular populations, very important populations, who are being denied access.

So, for example, take South Africa. We don't have places where men who have sex with men, where gay men, can feel comfortable to go for an HIV test. So they're effectively denied access. We don't have HIV testing campaigns that reach out to our migrant population, to our undocumented population. So, de facto, they are denied access.

We don't have HIV testing that reaches out to— we have tens of thousands of sex workers who must know about their vulnerability, but because they're criminalized, they are effectively denied access. So, the question is what does access mean.

And then to agree, is it access to HIV testing? Is that the access? Is that what we mean? Or are we meaning

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access to something of which HIV testing is the first part, and the second part is decent post-test counseling, and the third part is pap smears for women who test HIV positive.

And the fourth part is access to antiretroviral treatment for people who need access to antiretroviral treatment. And the fifth part is access to psychosocial services. I mean there's almost no mental health services, and the need of people with HIV for psychological support is often overlooked. So, it's not to say if any of these are not there that we shouldn't do it, but to do it and accept something that is less than meaningful access is very problematic.

SUSAN TIMBERLAKE: Alright. There are many issues again that you've raised, but there are two that I wondered if we could follow-up on. One is that we're talking about lack of access of people who want to test, and the other is we're talking about testing being used as in a coercive way so that you cannot get access to the further steps unless you test.

So, in this case, we hear about the situation where many women in antenatal clinics are told, unless you test for HIV, we will not provide birthing services, we will not provide treatment for you or your baby, we will not provide prevention of mother to child transmission.

We also know of course of other testing things where you have to test for HIV to be able to travel, to be able to migrate. You have to test for HIV to be able to uptake

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services for drug dependency. Could the group maybe comment on what that means when testing access becomes not necessarily a benefit towards greater health outcome but is done in a coercive way so that it's a prerequisite.

MOROLAKE ODETOYINBO: A little takeoff on something that is happening in South Africa, and that is the Know-Your-Status campaign and mass testing. The only way you can effectively have a mass campaign around knowing your status is if it's country-driven.

The government must decide that this is a priority. The people must decide this is a priority and then they will fall into that testing drive. If you have a situation like ours where only 4-percent, 6-percent of HIV services testing—whatever it is— is from the government and 95-percent from outsiders, there's no way you will have this kind of campaign.

So, in this conversation I'd like also bring in the role of the national government and look at funding for HIV services, not of HIV services, for health services really. Your gender will always be driven by whoever puts the money down, which means when it's time to get the numbers we'll ramp up the testing; when it's time to reduce we've cut it down.

Going into that and the question you asked in terms of why are we testing really, which is, I think, what this planet is all about, put in the HIV test itself to test. Why are we testing? I dare you to say it is of very little value to give

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me an HIV test if there's no follow-up service, because there are two things you will be.

If I'm HIV negative, you are going to give me the false notion that I'm immune to HIV infection, especially when everybody is at risk. You are going to give me that notion that yes, you are HIV negative and that is all, because there's no follow up, no counseling, no nothing. You just do this test.

Then if I'm HIV positive, where do I go and what do I do with this news you've given me? Where's the follow up? Where do I get services from? And that's why we say that HIV testing cannot be done on its own.

We can't have a campaign that just says, know your status, because knowing your status must be the first step to something else, which is different from the coercive nature of what we see in antenatal clinic where in some clinics, especially in the teaching hospitals and the big tertiary hospitals, we do not have a choice but to get tested because nobody will touch you without the HIV test.

So, if you are pregnant and you haven't been tested, you probably would never have access to services, and that's why women will just, once they begin to talk about HIV testing, they will go ahead and have their babies with traditional birth attendants or somebody who is not going to request for this HIV

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test because then it has become a means to an end, if that's a right word to put in here.

KATERINA JIRESOVA: I mean, it's kind of for me like the cost for a test. It's not the financial, like, how much you pay or how much does the health insurance pay, but what you pay for it. Like, in some countries, and it's about the Eastern or Central Europe, but in the European Union, if you are tested positive, you are not allowed to work in a sex work. You are off.

If you are HIV positive you are excluded from many services. In my country if you are migrant or you want to immigrate, you won't get a citizenship. It will be the direct fly back home. So, the question is, like, how can we— and I understand the health benefits. There are clearly health benefits to know your status to get to the treatment, but sometimes is the question, are they really, if they cut off your life in other ways?

PAUL WEKESA: Well, I would agree with what has just been said in terms of the need for strengthening the health systems in sub-Saharan in Africa so that we shift the focus from the entry point, which is testing, to what is available for everybody who tests, what is available after, because, as I said, I think the health system as it is right now is not even capable, is not strong enough to support what other problems exist apart from HIV.

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So there is a need to further strengthen, but the opportunity therein is that with HIV there has been some focus of this [inaudible], and so, there is an opportunity to utilize the fact that we are talking about what services are available to actually push and advocate for a focus from government and taking up of the commitments our governments will need to invest appropriately in the healthcare system, which is lacking.

MOROLAKE ODETOYINBO: [Inaudible] as we talk healthcare systems, we cannot talk as healthcare system in the content of HIV testing without talking community's spending system. We need to take HIV testing out of the healthcare setting into the communities, whether we choose to call this community strengthening or civil society strengthening.

CSS is an intrinsic part of HSS that we can't just focus on health care, health care settings or we try to change our healthcare settings without looking at these things going into the communities itself, and how can we keep talking about young people being at risk and the need for young people to know their status and they're testing positive.

In my country, if you are less than 18, you cannot get tested without parental consent. So, you go to school, young people want to get tested, but you know what? We cannot give them this test because they need the consent from a parent or whoever adult is in charge.

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As a young person I'm not going to bring my mother to check as I take my HIV test. Definitely not. And you can't be talking HIV test being universal if you're not also looking at children. Where are the PCL tests for new babies anyway? So, after all the so-called PMTCT services, what do we have for the new babies, for the children less than two years, less than 18 months, who have been born and who need to have access to testing.

JONATHAN COHEN: So, I think while I ask this next question I would encourage the audience to stand before one of the microphones— we have four of them— and prepare your questions. We talk often about the three C's of HIV testing: Consent, confidentiality, and counseling. We've also talked a lot on this panel about linkage to treatment.

Personally I sometimes think that the forgotten C in the three is confidentiality. It's one that we don't spend enough time talking about. It debates rage about informed consent. Counseling has become a big issue because we're talking about moving from extensive counseling to streamlined information, but confidentiality, I mean I would invite any of the panelists to talk about this: How important is it? How well respected is it, in your context? [Interposing]

MARK HEYWOOD: I think that confidentiality is of cardinal importance. People need the assurance at the outset that a positive result will be treated as a private result.

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That principle still stands. The practice is that it doesn't stand because the practice is that particularly in our poor countries there is no physical space to guarantee confidentiality.

Again, one of the criticisms I've seen about the our HCT campaign is that there aren't physical facilities for the counseling to take place, for the confidentially and so on to take place. So that's a challenge. But what I would say though is that confidentiality is really badly misunderstood a lot of the time.

A lot of healthcare workers think that confidentiality means that you counseled the person to secrecy about their HIV status, that you actively discourage disclosure. And confidentiality is often attacked because it's misunderstood. You can have confidentiality whilst promoting and encouraging disclosure.

They're not at odds with each other. You can have confidentiality even in the context of couple counseling. I mean, one of the things we're trying to do in South Africa, for obvious reasons, is to encourage sexual partners to come together for HIV testing.

Now, that doesn't mean that you throw the principles of privacy out of the window. So, I think it's critical, but I still think that God knows how many years into this epidemic;

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we're still getting it wrong in the way that we talk about privacy and confidentiality.

PAUL WEKESA: Just quickly. The paradigm has been, in Kenya, initially anonymity— it had to be an anonymous process— to now confidentiality, and we are sort of now moving with the focus on PITC. Obviously now the focus is moving from just confidentiality to shared confidentiality, which is a whole other issue, but in the health facility setting it becomes a reality we have to face and what that means for confidentiality.

JONATHAN COHEN: Katerina?

KATERINA JIRESOVA: Yes, well, I have a few stories maybe to describe it, like, we have good medical doctor who is a GPN. We can refer people living with HIV to her, but the nurse cannot know that the person coming is living with HIV. So, the doctor doesn't believe to her nurse.

Many people in my country are not trusting to and they have reasons not to trust that it will really stay in the room, so what they do is they go for a test to other countries. It's Europe, so it's small. It's one hour by train to come here to take a test, or two hours to Czech Republic.

And what it is even worse, it happens that they prefer not to go for a treatment, not to be registered within the health system in the country. Not to be in a danger that somebody will find out about your status. And they all undergo

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the treat, don't go for a treatment, so they got coming for a CDC4 and viral load or to Austria or to Czech Republic. Or they take the burden, which is much higher financial cost, that they are treated in a foreigner countries. And this is I think a very strong signal that there is a problem with the confidentiality.

MARK HEYWOOD: I'd just like to make a short point perhaps before the audience, which is I think we must be very careful about notions like shared confidentiality. I also had a problem when that was introduced in Botswana, because that takes away the confidentiality.

If shared confidentiality means that I'm the healthcare worker and I'm going to share it with somebody else whether you like it or not, that's not confidentiality. When the type of couple testing and counseling that I talked about gives people rights to privacy, but it doesn't take away the individuals autonomy.

Again, I've had discussions in China with people from the government about confidentiality. Well, I think that wherever you are in the world, privacy means something to people. I don't believe that culture or religion or whatever overrides people's fears of another person's negative reaction to them if they test HIV positive.

So, I promote disclosure, we must promote disclosure. But the disclosure has to come from within me, because I've

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decided that it's the right thing to do and that I can do so without harm to myself.

SUSAN TIMERLAKE: Yeah, I think this is one of the nuggets of the discussion that has never been put to rest and basically informed consent was important, and critically important, at the beginning of the epidemic and throughout most of the years because it relies on the notion that the individual, him or herself, is best placed to do the risk benefit analysis. And actually knows whether or not disclosure will destroy their lives or result in violence or whatever it may be.

The problem is that, there are two problems, one is that many, many people out there have never accepted that notion and feel like as a healthcare worker or as a government official setting policy, that disclosure should be mandated.

And the second is people argue that in this day and age, and Mark you brought it up yourself, that the risk benefit analysis has changed. That because we know now that people are incredibly less infectious if on treatment, we have yet another reason besides the healthcare of the individual to trust the person and get them on treatment as soon as possible, if indeed we do.

Now I'd like to take the first question there, right in the first. Let me take this one behind you first.

MALE SPEAKER: Okay, fine.

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SUSAN TIMBERLAKE: Sorry, you weren't standing up. The woman there, please.

DONNA FEDERMAN: Okay, thank you very much. My name is Donna Federman [misspelled?] and I'm a pediatrician and I've taken care of teenagers with HIV in New York for the past twenty years.

And I find this topic one that makes me incredibly sad and even angry that we continue to place so many of the problems of HIV and real discrimination and stigma at the door of counseling and testing.

As I said, I'm a doctor and for many, many years it's been clear that care is the human rights issue. That is the topic of this conference, Rights Here, Right Now, and one of the demands of our activist community and from the medical community, is universal access to treatment. And I am so troubled that HIV counseling and testing continues to be the place that people want to put a gate and a stop before letting people access care.

The HIV community is a very, very small part of the larger medical and social world in which exist. Most of the medical world does not really care about HIV, they're not motivated to offer testing, and our continued battle and struggle on this serves, I think, to confuse people as to what does the AIDS community really want? And what we want is access to care and an anti-discrimination.

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And I think, the part that makes me sad and angry is I think we, although you have said this is complicated, I don't think it's so complicated, and I think we need to let go the notion that we're going to fight this battle at the doorstep of counseling and testing. There is no other disease that we have made the big deal over whether or not people get their diagnosis.

HIV is a medical and a social problem, and we need to fight those on their own merits, not by preventing people from knowing their status.

And I think some of our speakers from Africa have eloquently spoken about there's real problems in HIV but don't make it be about counseling and testing. Make that easy so we don't waste precious resources on fighting over something that is a gateway to care and services. Thank you [applause].

JONATHAN COHEN: I'll ask our panelists to respond.

KATERINA JIRESOVA: I would say people haven't had been in the queue for awhile, so if we just take this words standing we will go and do this together.

JONATHAN COHEN: I'm going to do maybe this one first because it's so fundamental and then we'll take a couple more.

KATERINA JIRESOVA: Okay.

MARK HEYWOOD: I respect the view that's just been articulated. And there's no doubt in my mind that it's a human right of access to care and treatment. And there's no doubt

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that HIV counseling and testing should be an open door rather than a gate as you've described it.

And you've talked from your experience as a pediatrician, I'll talk from my experience as a provider of counseling and legal services to people who've been tested, and in all my experience with thousands of people in 15 years, one of the deep lessons I've understood is that the quality of the counseling and the quality of the testing will determine whether a person lives positively with an HIV diagnosis or very negatively with a HIV diagnosis. And that where people do not get proper counseling and proper testing they can be traumatized for years with the fear.

Now, that may not be the case in New York where people can get access to knowledge, but it is the case in Africa where people are poor, do not have access to the internet where they live in hostile communities, etcetera.

Let me give you a question, if you were out with us on the human rights march the other night, you might have seen the video made by Annie Lennox of a woman in Lusikisiki who killed herself and killed her four children, four youngest children in committing suicide. Now, my question to you is why did she do that? What is it that causes somebody, what type of HIV test did she get? What type of treatment and support did she get?

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And the other point that you make is that the people have a human right to treatment, but in my part of the world, a test does not automatically lead to treatment.

So, if a test is something that automatically leads to discrimination but doesn't lead to treatment, then we've got to focus on the entry point. So in many ways, I think we think the same. But, I think that my world is very different from yours.

SUSAN TIMBERLAKE: It may be different, [applause] but for -

JONATHAN COHEN: So, before you start, I'm going to allow -

SUSAN TIMBERLAKE: For the past ten years -

JONATHAN COHEN: Excuse me, I'm going to allow just a thirty second response.

SUSAN TIMBERLAKE: Let me just answer for one minute.

JONATHAN COHEN: Okay? Thirty seconds.

SUSAN TIMBERLAKE: Yes. I've been working in South Africa for the past ten years and for the past five years we've been working with the Western Cape Province Public Health Service on scaling up counseling and testing, so my experience is not just in New York.

Testing is a moment in time, people with HIV live a very long life for many, many years. And even a horrible initial counseling experience can be overcome with good care.

MARK HEYWOOD: With good care.

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SUSAN TIMBERLAKE: None of us - or with any care. It's not the only moment.

MARK HEYWOOD: Not with no care.

SUSAN TIMBERLAKE: And I think the extraordinary focus on counseling and testing is doing a disservice to what needs to be a continuum.

I was on that Human Rights march, I've been an activist as well a doctor for the entire epidemic, and I'm telling you we don't need to just keep focusing on testing. If the energy and the passion of the human rights campaign left the counseling arena and just focused on the right of access to treatment and making proper linkages, we would end a lot of the confusion and accelerate something that we desperately need, which is people knowing their status and fighting for life saving care [applause].

JONATHAN COHEN: So, microphone one and then three.

ALAN MALECHA: Thank you for the session from the panelists and the chair to the session, my name is Alan Malecha [misspelled?], I'm a human rights lawyer practicing in Kenyan health and human rights issues.

I have two very short questions, but I'll have to give a background to them. The first question is, I'm trying to understand this, are we, and maybe the medical practitioners in this room can help me, are we as lawyers blocking your way in treating people by fighting for the right to autonomy?

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And my reasoning of this question comes in the sense that in Kenya it has taken us seven years to get into place a law that can create a legal firm or to deliver HIV and human rights issues. A lot of resistance was met by researchers who are cross with us as lawyer putting a clause in the law, saying that you have to get consent before you carry out research.

And at time this been argued by Kevin Decoc [misspelled?] that HIV is an emergency. We need to lift the niceties of consent and test people and get them on treatment. We all know what happened in Cuba.

Recently when we're doing the East African bill and sorry to say here Susan, but when we were doing the East African bill, we had the Kenyan representative from UNAIDS whose a doctor, challenging our provision on testing and counseling and saying we are still old fashioned, we're still a archaic as lawyers, why do we still insist on consent? And their people who don't need free test you can directly contest.

So, the first question is, are we as lawyers, blocking the medical practitioners in getting people to access treatment by protecting the right to autonomy?

Relating to confidentiality, we all know that stigma, especially in the African countries and I believe in Eastern Europe is the reason we advocate for confidentiality. Susan clearly said you must be a risk analyst to know when can I disclose? But unless you guarantee that it's not going to be a

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human rights violation if you disclose, then we won't need confidentiality.

So then my second question then goes, and maybe Mark you can help on this, what are we as lawyers doing about stigma, given that stigma is not tangible legally, you can't hold it, you can only address it through discrimination.

What are we doing as lawyers to deal with the aspect of stigma that would go a long way to making HIV an acceptable disease? Thank you.

JONATHAN COHEN: So we're going to take another question here, and then we'll ask the panelists. And microphone two.

JIMMY: Could I be [inaudible], please?

JONATHAN COHEN: No, microphone three, I'm sorry.

JIMMY: Yes, my name is Jimmy and I'm from Western Cape. I'm an executive director there for public health programs, and HIV and AIDS fall within my portfolio.

So, first maybe just to say thanks to the panelists for the good job for sharing experience with us. As Mark said, if we had all the time we could spend the whole day sharing the experience from South Africa.

Whilst I would tend to agree largely with the systemic challenges that Mark has listed for us, maybe from our experience as well is that some of it might be out of date, because we're three months down the line. Not that they don't

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need attention, they do, and maybe just one or two experience from Western Cape.

We, and this is the basis for my question too, colleagues from Kenyan, other countries, is one of the cardinal requisite we have identified for ACT is that you really need to make sure that before you start with day one, your logistics, your systems, your preparedness for training, everything has been done. And that's what we've done in Western Cape.

That, before we started with day one that we showed that all the systems, particularly the logistics, test kids that your [inaudible] they, the private sector, everybody. We've got a network that is already, we've got our ducks in a row, to ensure that those that are testing outside as they've got the right to as kids, the right materials and so on and so on. Staff has been trained.

So unless, our experience was that once you've done that, then you ready to can start. So my question maybe to Kenyan and other colleagues from other countries is whether, what is your experience in managing the logistics and preparing for the ACT? Thank you.

JONATHAN COHEN: Okay. Morolake, why don't we start with you?

MOROLAKE ODETOYINBO: What bad testing goes to people is lifelong. Unfortunately, it's not just something you can wish away.

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Twelve years ago, I tested HIV positive because my husband was in the military, he was flying and compose really, you have to the HIV tests if you're part of the crew. He had gone solo when, and I know our HIV test came out positive, and what he was told is, the Nigerian Air Force cannot invest millions in a man who would soon die. How do you say that to a human being?

Now, his motto in life, any day, any time, was born to fly, that's what he believed he was created to be. And with one sentence, all of that was thrown out. Now, what happened after that test is he became a totally different human being. I could not recognize him. Self-destructive, when you're self-destructive you destroy everything in your path.

So, its 12 years down the line, at some point I had to take myself away from that situation, because I want something else for my life. But 12 years down the line, he has still not been able to come to terms with it, so he knows it head wise, but believe me what has happened to the past 12 years, you can't even begin to imagine.

So, yes we need people to know their status, we need people to access services, but we can never, ever underestimate what it means when you get bad testing, or zero counseling. Because the effects are there for a long time.

So just to put that on the table, that people don't just get over it, it doesn't always happen. Thank God for the

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lawyers [laughter]. Without for law, I wonder what we would have been doing with HIV testing.

Because you see its one thing to say are the lawyers preventing people from getting tested is the other thing to say at least there's something that checks the madness around HIV testing. When a University decides that you will need to show that you do not have HIV and that you are not pregnant before you graduate, it's insane.

And I'm talking from a Nigerian experience where a university is cited on that, that you cannot graduate from our Christian college, except you are HIV negative. Crazy, out of four years in the university. When you get tested to get a job, when if you are positive you cannot be in school, when my child cannot go to boarding school because that child has HIV, so it's beyond just access to medication. W

hat is the use of life if there is no quality life? What's the use of life if you just give your piece to stay alive? I don't want to be alive when that sort circumstances, because I still desperately need my dignity as a human being [applause]. And I won't give it in, yet in spite of these [inaudible]. So, just to say you see, while we check about the HIV testing, please don't let it get underestimated, because what it does in the lives of people is not something you can begin to see.

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So I hate the lawyers some of the time, but when it comes to HIV I love them [laughter]. Right now, we're in court, Nigeria because First Bank has decided to throw somebody off work, and we went to court, guess what the lawyer, their lawyer said when he got to court? He's challenging the right legal state has to pass a anti HIV legislation. That's what the guy, we came to court to challenge the right of the government who passed that law.

And so, okay so all friend of the court are good, but these are things we need to happen, otherwise it mindless discrimination that goes on is not something that we can begin to deal with.

SUSAN TIMBERLAKE: You want to say something?

KATERINA JIRESOVA: Yeah, I'm always kind of, for me consent and giving agreement, it's respecting people and not within HIV only, but I expected this to do my doctors in any other diseases or issues.

Whenever my doctor is going to test something for me, she always inform me, I agree. Which I know it's not the best, but I feel very strong then. And even I decide, and this outside of HIV, that I don't take this way of treatment for different issues. I know it was my decision, and I took the responsibility over it, but I almost can't say no, and I think this is like, there's basic respect.

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PAUL WEKESA: I'll just make a quick point, I know we need to get more questions. I want to shift focus a bit to what Dawn said, and which I agree with. That there is farther grant for further activism, further push, for us to improve the health systems. That goes hand in hand with access to testing. And I think that is farther grand that needs to be explored farther for activism. Governments are not investing enough, and they should invest enough.

MARK HAYWOOD: Let's here. I'll come back later.

JONATHAN COHEN: Okay.

SUSAN TIMBERLAKE: Okay, this is incredible because we, I think we're just getting into it and we got five more minutes and this is ridiculous. I'd like all three people who are lined up to go ahead and speak your mind, ask your question and then maybe we'll have a little summation or last comments those up here. I'm not sure who was first. Okay, is it number two there? Please.

MIA ANGECA: I think so. Let me introduce myself Mia Angeca [misspelled?] from [inaudible] Medical University. Just referring to the speaker from Nigeria and the stigma which a sign, HIV in fact that people may face. Let me give you the example from the United Arab Emirates where I have been working for several month as a visiting professor.

In this very country, people are mandatory tested for HIV, just because they are going to get married, just because

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they are in-patients, just because they are entering the university, etcetera.

And people who are HIV infected are immediately reported to the police [laughter]. So, if we are talking about confidentiality, we must think about some examples. What do people face? And to believe me, according to our research the stigma in the UAE is enormous.

Some of our respondents, we made a study among 2,000 students from high schools in this country, so many of them were just writing in the question or if somebody from my family, my relative will get HIV infection, I will just kill such a person. So these are their attitudes towards HIV infected persons.

So and what is more striking, about one third of young people who were asked about the situation in which their future husband or future wife will be HIV positive while tested, claimed that they will reveal their sero status to the police, their beloved ones status.

So, what are we talking about? Confidentiality, human rights, etcetera, I think that there are many, many issues which we should address and which we should overcome of course, because of some cultural issues, some religious issues, etcetera. But of course because of laws which we are talking about now so, just my -

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JONATHAN COHEN: Can I thank you for your comment very much? And let the others speak, thank you.

SUSAN TIMBERLAKE: It think it's Ginny in the back, is that Ginny? Okay. Whichever. Go ahead.

FEMALE SPEAKER: Is it me? Okay, thank you very much for your lovely presentations. I'm from South Africa, and maybe just a comment.

The Western Cape is very different from other very poor resourced areas of South Africa. And there is so much inequity even within miles of going from the Western Cape to the Eastern Cape, so I don't think it can be with all due respect a good measure of the equitable access to treatment and services in South Africa. But that wasn't my point, the question I have is also the genderness of HIV testing.

Over the years we have seen that the barren of testing has been on women, and often when they come back home, part of the problem with coming back with a positive diagnosis, even when they access treatment, is whether or not they will fear being evicted from the house, they will fear being abandoned, and the poorer they are, the worse they are.

So my question to all of you, especially you Mark, is to find out how well we have done to reach men in the million people who have tested in South Africa since the campaign? And also the other question is around what tools do we have to find

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out how testing is beneficial for people who are negative?

Thank you.

GINNY PAL: My name is Ginny Pal [misspelled?], I'm also from South Africa and I'm going to continue with what the former speaker spoke about.

We've recently done some research on three sites in South Africa on pregnant women's experiences of being tested at anti-natal clinics. And overwhelming their experiences were that their rights were not being respected and overwhelming the test and the way that their right weren't being respected influenced those women not to actually enter into treatment.

Which calls into question and really endorses, does the ends justify the means or whatever the statement is. But the thing that really concerns me as well, about the 15 million, and we work in a small rural area of [inaudible] is, are there really resources in a country to back up the services that are required to service those 15 million, when they want to enter into treatment programs?

Just to give you an example, the local hospital that services the area we work in should have a compliment of eight doctors, which at the it most doesn't really meet the need. At the moment they have two. And we're actually entering into an amazingly ambitious process and aren't we raising people's expectations for them to be failed? And what we doing when we do that?

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JONATHAN COHEN: So, thirty seconds? I think we have time for each panelist to conclude with about thirty seconds [laughter]. I know that's not the most respectful, but the floor is yours if you'd like to make a concluding comment please.

MARK HEYWOOD: 130 seconds [laughter].

JONATHAN COHEN: Maybe someone will lend you those.

MARK HEYWOOD: Let me just, what I get from this discussion is the clarity that human rights violations around HIV testing are not a thing of the past by any stretch of the imagination, they continue today.

I don't think that law can deal with stigma, but law is necessary, but we need strategies to deal with stigma. As you say, stigma is much less tangible, it's a critical thing.

I don't think that lawyers by protecting people from violations of human rights are blocking their access to doctors. We get very good doctors and very bad doctors. And the purpose of this discussion is not to block access to treatment, it's to ensure that people get access to a good quality of treatment, and that there's a continuum of care that starts with HIV testing and go all the way through.

Just to the specific questions that were asked to me about South Africa, let me make it clear, I've agonized over South Africa's HIC counseling and testing campaign from a human rights perspective, but in my agonizing I've come out in

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support of the HCT campaign, because I've had to look at human rights, from a variety of different angles as well as the necessities of how we are going to get ahead of the epidemic in South Africa.

And at this point I still support the HTC campaign but I do so saying that we have to identify honestly the gaps, and try to fill those gaps as we go along.

The question was as asked as how well are we reaching men? The problem is we don't know at the moment. And that's a very good question and that's one of the questions we have to be answer because we do know that men are not testing for HIV in the way that women are forced to test for HIV through pregnancy.

One of the benefits of people who are HIV negative, we don't know at the moment. We've got to be able to answer that question, because part of this thing is about getting people into care and about keeping people negative. So that question can't disappear from our sight.

The last question about are there resources, well one of the biggest problems of this campaign is that it hasn't had, it's what in South Africans would now call an unfunded mandate. It's a massive campaign with no proper money put behind it and that's going to be one of our biggest challenges, but I believe that we use this campaign to fill the health system with

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doctors, with nurses, with the necessary resources, etcetera, rather than say that we're going to have to wait.

Because if we have to wait, we'll wait for a decade until the day we can say that we've got the resources. And in the decade that we wait, people will die while they're unable to get access to treatment, etcetera. So, we have to use this to catalyze, to force progress.

KATERINA JIRESOVA: Well, I mean I have so much things in my head, like it will be for couple of other sessions. And what I'm having this strong somewhere like I want to be quiet when it's like this, like this balance of power. And I think it was over and over mentioned here in different examples, that as the professional we have a bigger problem many times than now of the people we treating or meeting or serving and whatever we do when we try to balance this power, most of the time it just don't work to be equal because simply we are the one who are providing services.

We are having something in a hand. And that's good to know and to always remind at least to myself that the hardest work sometimes, and I think the same for parents, is to give the freedom to people.

MOROLAKE ODETOYINBO: Thank you very much. Children need to have access to services, it is unacceptable that our children are not being tested. Its unaccepted that our children

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born with HIV, are dying before their second birthday, simply because there's no access to testing for children.

So my message is, as we talk about testing, we really seriously must address the issues of children, of infants who have no access because they can't do the rapid test. We must address young people, where you have legislation that makes it impossible for young people to access services if you're too young.

We must wake up and realize that in Africa we have men who have sex with men, and they need to have access to services. And it has to go beyond lip service. Gender based violence is something that is so much a part, we're seeing so much of it intertwine with HIV. Because really when this woman test HIV positive, can she go back home? Can you go home and tell your husband, I tested HIV positive?

We believe that whoever gets to know first is responsible. And because women are the ones who are tested, either because she's pregnant or because her child is HIV positive, it's the women who are facing all of this once again, and so just let's think creatively along treatment, around testing, and remember that the most important person is that one right in front of you.

And my needs, what I've expressed, are the most important things, not what you think is best for me, but what are my immediate needs and I'm [inaudible].

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PAUL WEKESA: Thank you very much for the participation. I would say, I would want to emphasize one point. I think I've said it already three times, there is space for advocacy to ensure that we can improve the health systems even in Africa.

Africa has resources, but these resources are wasted because we are not pushing hard enough to ensure that there is appropriate investment. Corruption alone, the funds that are lost from corruption alone, would be able to improve the health system.

That is an open advocacy platform, and I'd encourage Alan who is from Kenya, and others, to take that up. Because we can win that if we push for it.

I'm glad that in Kenya we have innovative strategies, and I'd be happy to share with other countries, because for example in terms of reaching men, there was a question about that, during the welcome campaign, there was a testing campaign to target men, up to 70-percent uptick by men, which was brilliant. To take on the question that had been asked about systems for mass testing, even in Kenya we have a problem.

The focus has been, funds are available for testing, but are the logistics and the systems, the human resource capacities and treatment, have gaps. Thank you very much.

SUSAN TIMBERLAKE: Okay, I really want to thank all our panelists. I think it was an incredibly exciting session. We

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heard lots of different messages. And I think one of the biggest messages we, a couple of them were, we should keep people alive by making testing as available as possible, make it come in many forms, easy, accessible, confidential, and when it comes in the healthcare service, it should also come with dignity and training and support for healthcare workers.

And I understand the message of the person who's said, don't put it all on the testing and counseling, and it's a very strong message that there needs to be much more funding to deal with the social issues that go beyond the healthcare systems, and beyond testing, and that is stigma and discrimination.

And I think as activists and as people working on these issues, we have to constantly be treatment activists, that demand treatment as a package, and demand that funding goes to ensuring that there a continuum from testing to treatment where patients are supported to stay in the system, are supported against discrimination, and actually do benefit from the experience of testing so that they do get treatment, and they are able to continue to live, as Mark said successfully, with HIV. Thank you all, and keep up the fight.

[END RECORDING]

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