





# **DISCUSSION REPORT**

University of Cape Town's Students' Health and Welfare Centres Organisation (SHAWCO Health) – Médecins sans Frontières / Doctors Without Borders (MSF) Public Debate 5 May 2011

## Mandatory Testing For Hiv And Treatment As Prevention:

## Two Sides Of The Same Coin?

"New Scientific evidence shows that treating people for HIV not only fights their own illness but also stops HIV from spreading – in fact, the evidence is that people on antiretroviral (ARV) treatment are 90% less infectious than those not on treatment. This opens up a whole new world where we not only treat the individual with ARVs but we can aim to reduce new infections at the community level too." Dr Isabelle Andrieux-Meyer, HIV advisor, MSF Access Campaign<sup>1</sup>

## **Biographies**



# Professor Bongani Mayosi DPhil (Oxon), FCP (SA), FESC, FACC, FRCP, MASSAf, OMS

Prof. Mayosi was appointed to the Chair of Medicine and Headship of the Department of Medicine at Groote Schuur Hospital and the University of Cape Town in 2006. His research Interests and activities include genetics of cardiovascular traits; treatment of tuberculous pericarditis and the prevention of rheumatic fever.



#### Dr Gilles van Custem

Dr van Custem is the medical coordinator for MSF in South Africa and Lesotho. He is a medical doctor with diploma in tropical medicine and also holds a master of public health from the university of Cape Town. He has been working in the field of HIV and TB in Africa for more than 10 years, of which the last 7 years in MSF's project in Khayelitsha.



#### Pholokgolo Ramothwalo

Mr Ramothwala has been living openly with HIV for the past 13 years. He is a journalist by profession. His work experience in the HIV field includes working with Treatment Action Campaign, AIDS Law Project, Love Life, UNAIDS and Soul City. He serves as an advisory board for Oxfam joint HIV/ AIDS programme and the HSRC's House Hold HIV/AIDS survey. He is the founder of Positive Convention.



#### **Professor Leslie London**

Prof. London is a Public Health Specialist and Director of the School of Public Health and Family Medicine at UCT. He also heads the Health and Human Rights programme and is Associate Director for Environmental Health in the Centre for Occupational and Environmental Health Research. He is a recipient of awards from Alan Pifer Foundation and the Society for Occupational and Environmental Health for his work on the hazards of pesticides for farm workers.



#### **Dr Janet Giddy**

Dr Giddy, is a Family Physician with experience in Rural Medicine, Obstetrics, Primary Health Care and the education of health workers and medical students. She is a member of the Medical & Dental Board of the Health Professional Council of South Africa (HPCSA). She has focused on HIV care for the last 10 years and was the HIV Programs Manager at McCord Hospital, Durban till 2010. She is studying Public Health and has publications related to rural health, primary care, STI's, obstetrics, and HIV.

### **Discussion participants:**

Dr Gilles van Cutsem (GvC) Mr Pholokgolo Ramothwala (PR) Prof Leslie London (LL) Dr Janet Giddy (JG) MSF Medical Coordinator, South Africa and Lesotho Founder, Positive Convention

Director, School of Public Health and Family Medicine, UCT Family Physician & former HIV Programme Manager, McCord

Hospital

Facilitator: Prof Bongani Mayosi Head of Department of Medicine, UCT

MSF and SHAWCO Health at the University of Cape Town (UCT) partnered to bring to the public a high-level debate that sought to engender critical thinking on health issues. The debate focused specifically on whether mandatory testing and treatment as prevention could be critical elements in reducing the HIV infection rate. The report provides a summary of the discussion and highlights key issues that emerged from the debate.

### Welcome

**Prof. Bongani Mayosi**-Head of Department of Medicine, UCT, set the scene for the evening's discussion by highlighting the importance of the continuous debate and innovation in the HIV treatment field: "The problem of HIV and AIDS is a formidable one, and we have to continue thinking of new ways of dealing with this. This evening's discussion is at the leading edge of debates on how to deal with this epidemic and reverse the spread of HIV."

### Introduction

#### Sharon Ekambaram, Head of Programmes Unit, MSF South Africa

MSF has worked in Khayelitsha since 1999 providing antiretroviral treatment. In the bleak days of denialism, MSF provided scientific evidence proving that ARVs could prolong the lives of people living with HIV, as opposed to the quackery that was being presented. MSF was able to provide models of care in resource poor settings, proving that treatment could be provided irrespective of the context of inequality. Today's debate puts us in the new phase of the challenges that we are facing for us to improve access to treatment for all those that need it.

"What we want to do as MSF through these debates is to develop a culture of what it means to be a doctor and to look at individual acts of humanitarianism. So let us take this debate forward, to not only change policy, but also to change the way we look at our own profession and what we are doing," Ekambaram said.

#### Kamlin Ekambaram, Marketing and Events Manager, SHAWCO Health

SHAWCO Health was established in 1943 by a medical student who was driving an ambulance in the Metro to make extra money. He noticed the inequality and need for a mobile clinic in the greater Cape Town metropolitan area. SHAWCO Health provides free primary health care to underserviced areas of Cape Town, in order plug the holes in the health system which the government is yet to plug.

SHAWCO has six weekly adult mobile clinics and 2 paediatric clinics. In 2010 alone, SHAWCO ran over 200 clinics by over 600 volunteer students, which came up to approximately R200 000 of donated consultation time.

## The Biomedical Approach: An MSF perspective

#### DEBATE: OPENING REMARKS BY PANELLISTS

Dr Gilles van Cutsem argued that adding a biomedical approach to the current HIV prevention efforts which up until now have focused primarily on individual behaviour change is necessary to win the fight against HIV. van Custem made specific reference to a study based on a mathematical model by Granich, Gilks, Dye, De Cock and Williams of the World Health Organisation (WHO)<sup>2</sup>. The study shows that if you test everyone for HIV, and start ARV treatment immediately after testing, you would likely eliminate HIV within ten years.

#### The global current HIV landscape:

"The epidemic continues to outpace the response with two people newly infected for every individual who started ARV treatment in 2009" 3-Ban Ki Moon, United Nations Secretary-General,

Global HIV data from 2009 reveal that: 4

- there were more than 33 million people living with HIV in 2009.
- 1.8 million people died from HIV in 2009 alone
- every day, there are 7,000 new infections, of which 1,000 are in children.
- in the past decade, more than 6 million people have been started on ARVs, however, today more than 10 million people still need ARV treatment.
- while 1.2 million people started on ARVs in 2009, 2.6 million people became infected during the same period.

Dr Van Cutsem also noted that despite the incredible successes and need regarding antiretroviral scale up, there is what is now called the "AIDS funding backlash," with the total annual financial resources available for HIV programmes reaching a plateau for the first time in late 2007 at almost USD 16 billion. <sup>5</sup>

The number of new HIV infections peaked during the late 1990s and is slowly decreasing, however this decrease in new infections is small. According to UNAIDS<sup>6</sup>, this decrease is ascribed to the following factors:

- Behavioural change
  - Increased condom use
  - o Decreased multiple sexual partners
- The natural evolution of the epidemic

Van Cutsem continued to state that, until now, most biomedical attempts to decrease new infections of HIV have had limited success. However, he mentioned the successes of the following interventions:

- Male circumcision: Through several trials, it has been shown that male circumcision can reduce female-tomale sexual transmission of HIV by up to 60%.7,8,9,10
- Pre-exposure prophylaxis (PreP): The taking of ARVs by HIV-negative people to prevent acquisition of HIV has shown to reduce sexual infection of HIV by up to 44% in men who have sex with men in a small study<sup>11</sup>. However, the FemPrep12 study, the same type of study between heterosexual couples, had to be discontinued prematurely because no effect was shown to protect women.
- Microbicides: A tenofovir-gel, applied in the vagina, can modestly reduce the number of new HIV infections in women.13

The most promising concept in the fight against the spread of the epidemic according to Dr Van Cutsem, has been the mathematical model presented by Granich et al<sup>14</sup> which shows that if you were to test everyone for HIV, and start ARV treatment immediately after testing, you would eliminate new HIV infections within ten years This strategy is commonly known as 'Treatment as Prevention'.

Evidence for Treatment as Prevention: Viral load (which measures the amount of HIV in the bodily fluid) is associated with infectiousness. This means that the lower the viral load, the less infectious a person is.15

Available at http://www.hivcenternyc.org/documents/LancetTestandTreat.pdf

<sup>3</sup>United Nations Report of the Secretary-General, 28 March 2011.

Available at: http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/20110331\_SG\_report\_en.pdf

<sup>4</sup>United Nations Report of the Secretary-General, 28 March 2011.
Available at: http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/20110331\_SG\_report\_en.pdf

<sup>5</sup>United Nations Report of the Secretary-General, 28 March 2011.

Available at: http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/20110331\_SG\_report\_en.pdf 6UNAIDS Report on the Global AIDS Epidemic, 2010.

Available at http://www.unaids.org/globalreport/global\_report.htm

Auvert B et al. Impact of male circumcision on the female-to-male transmission of HIV. IAS Conference on HIV Pathogenesis and treatment, Rio de Janeiro, abstract TuOa0402, 2005

Auvert B et al. Impact of male circumcision on the female-to-male transmission of HIV. IAS Conference on HIV Pathogenesis and treatment, Rio de Janeiro, abstract TuOa0402, 2005

Bailey RC et al. Male circumcision for HIV prevention in young men in Kisumu, Kenya: a randomised controlled trial. The Lancet 369: 643-56, 2007 Gray RH et al. Male circumcision for HIV prevention in men in Rakai, Uganda: a randomised trial. The Lancet 369(9562):657-66, 2007

"Grant RM et al. Preexposure chemoprophylaxis for HIV prevention in men who have sex with men.N Engl J Med. 2010 Dec 30;363(27):2587-99.

12See http://www.niaid.nih.gov/news/newsreleases/2011/Pages/FEMPrEP.aspx for more information

 <sup>13</sup>Abdool Karim Q et al. Science. 2010 Sep 3;329(5996):1168-74
 <sup>14</sup>Granich RM et al. Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model. Lancet 373 (9657), 48-57, 2009

<sup>5</sup>Quinn TC. et al, 2000, NEJM

<sup>&</sup>lt;sup>2</sup>Granich RM et al. Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model. Lancet 373 (9657), 48-57, 2009.

When people adhere to successful ARV regimens, their viral load becomes very low and they are less likely to pass the virus to their partners or, in the cases of expecting or new mothers, their babies.

- ARVs can prevent HIV transmission this logic follows from providing ARVs to prevent transmission of HIV from mother to child.
- The HPTN 052<sup>16</sup> study of couples where one partner was HIV- infected and the other was not, showed that study found that people on ARV treatment were 96% less likely to transmit HIV to their partners than untreated people. This study randomised the positive partner in heterosexual couples either to start taking ARVs immediately, at an average CD4 count of 436 cells/mm3, or to delay taking them till their CD4 count fell below 250 cells/mm3. The study had to be stopped three years earlier than planned due to the interim results.

#### Feasibility:

Dr Van Cutsem referred to a statement<sup>17</sup> made by Dr Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases in the United States of America, highlighting that"rather than saying it's an all-ornothing phenomenon — that we're going to eliminate the epidemic without anything else but test and treat — what I argue for is, why don't we let test and treat be part of a more aggressive prevention armamentarium. I would be satisfied with the epidemic if not disappearing, then at least declining; and I see seek, test and treat as one of several tools in the tool kit that will get us there".

Van Cutsem stated:

"The concept of Test and Treat also blurred the distinction between treatment and prevention, because it shows that treatment is prevention. Not only does treatment reduce mortality, but it also reduces new infections."

There is one American study<sup>18</sup> that shows that when you examine how many people are aware of their HIV status (estimates indicate 75% of people who are HIV-infected, know their status); they are only responsible for 30% to 40% of all new infections. This means that the majority of new infections are accounted for by people who do not know their status.

He said that the major problem is that people are not testing for HIV. If they are not testing for HIV, you cannot start them on treatment and they cannot change their behaviour.

Van Cutsem urged that the focus needs to be on the number of people who have never tested for HIV and stated:

"Thirty years into the epidemic, 25 million people have died and 60 million people have been infected. Despite the successes that have been made, the epidemic continues to outpace the response. Coupled with that, we have dwindling political and financial support. If we don't show today that we can do things differently and that we can push back the tide of HIV, then we will not regain that support."

In closing, Van Cutsem urged for a radical biomedical approach that combines treatment and prevention measures in the same strategy and implementation model.

## My experience: A perspective from a person living with HIV

Pholokgolo Ramothwala, was diagnosed HIV-positive in 1997. He stated that he used to be against mandatory testing, but thought that change is needed in the way HIV is dealt with today.

Ramothwala argued that the risks and benefits of HIV testing have changed, with new ARVs having less sideeffects and overwhelming evidence showing that early initiation of treatment is effective.

<sup>&</sup>lt;sup>16</sup>Cohen M et al. Antiretroviral treatment to prevent the sexual transmission of HIV-1: results from the HPTN 052 multinational randomized controlled ART. Sixth International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention, Rome, abstract MOAX0102, 2011. 
<sup>17</sup>Nature 463, 1006 (2010) | doi:10.1038/4631006a

<sup>&</sup>lt;sup>18</sup>Marks G., et al. Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA. AIDS: 26 June 2006 - Volume 20 - Issue 10 - p 1447-1450

Previously, he thought that mandatory testing was a bad idea. He said that it was because it took him some time to develop the courage to be open about his own HIV status.

Mr Ramothwala said the approach of offering voluntary HIV testing to patients has had limited success in preventingnew HIV infections, and ensuring that people living with HIV to live long and healthy lives..

"Can we force people to test? Obviously, no, but we need to do something more drastic than we are doing now."—Pholokgolo Ramothwala

He mentioned that people feared being tested for HIV:

"I hear stories on a daily basis from people who will tell me why they are too scared to get tested. It is the same people, and I saw someone like this a few weeks ago, who lose weight until they are 32kg. I said to him, "Are you now ready to be tested for HIV?"

"We need mandatory testing for people like him because he now looks desperate. He wants to live, but he only found out that he has HIV when his CD4 count (a measure of the immune system's strength) was almost at zero. Why are allowing ourselves, as people living with HIV, to get to that point?"

Ramothwala posed the following question to illustrate his point: "When we say people should have the choice to test for HIV, are we not encouraging the shame of being HIV-positive?"

He went further by expanding on the dilemma. "When we allow people, the choice to go home to think about getting tested until their CD4 count is incredibly low, we as medical practitioners know that when people come back at that point, ARV treatment is more difficult to tolerate."

In conclusion, Ramothwala noted the importance of recognising the dilemma in balancing human rights, the personal safety of someone unknowingly living with HIV, and the obligation of medical professionals. Ramothwala urged that it was time to consider mandatory testing as an option to decrease the HIV infection rate.

## Individual rights vs. global good: A human rights approach

Prof. Leslie London argued that mandatory testing may cause more harm than good, and questioned if mandatory testing was the right way to make people aware of their status.

In his argument, London spoke about the International Covenant on Civil and Political<sup>19</sup>, the main human rights covenant, which says that individual human rights can be limited when these are outweighed by what is in the broader public interest.

Prof. London highlighted the following principles which must be met in order for it to be permissible for rights to be limited:

- The restriction must be provided for in law and must not be arbitrary
- The objective needs to be legitimate
- · The rights-limiting measure is necessary in order to achieve the objective
- Importantly, no other measure that is less intrusive may exist in order to achieve the objective
- That the restriction is not discriminatory

Prof. London offered a series of questions, that he said should be answered before deciding on whether or not mandatory testing could be justified as a policy:

#### 1. What might be the point of mandatory testing?

Firstly, to get people onto treatment. If more people get tested through mandatory testing, more people will be able to get onto treatment. Treatment is also a form of prevention of new infections. Secondly, mandatory

<sup>&</sup>lt;sup>19</sup>Available at http://www2.ohchr.org/english/law/ccpr.htm

testing may also protect third parties, people who are not HIV-infected. If you force people to test, then hopefully you will be able to protect people who are uninfected. Thirdly, we might also argue that mandatory testing is part of taking stigma away, in that if HIV testing became more routine, people will be less stigmatised. Each rationale should be examined in turn below.

#### 2. How effective is it likely to be?

There is a big gap between the number of people who need to be treated and those that are on treatment. We have just raised the CD4 threshold of people getting onto treatment. We are looking at a large increase in the number of people getting onto treatment, and who will need to be on treatment for a long period of time. If we introduce mandatory testing and suddenly have a huge influx of people needing treatment, what will the implications be for our health system? Are we simply going to start more people on treatment and not see them through, and then have the problem of drug resistance developing? Mandatory testing may be more effective at getting more people to start treatment but it will only be effective if we have a whole range of other interventions at the same time to increase the number of people we get onto treatment.

In terms of the second potential objective of protecting other people, there are studies that show knowing your status does protect other people from infection and that uptake of voluntary counselling and testing (VCT) does decrease the risk for uninfected people. However, these studies are based on VCT, and we are talking here about mandatory testing. This is about people who would not have come forward to be tested otherwise. Is it realistic to expect them to change their behaviour after being forced to take an HIV test? I think there is no evidence for that and I would be doubtful that persons who are reluctant to take a test would suddenly become adherent in terms of reducing their risky behaviour.

In terms of the third potential objective, to reduce stigma; I do not see how mandatory testing would of itself reduce stigma. There are many other things that need to be introduced to change the effect of stigma.

#### 3. Is it properly targeted?

Mandatory testing implies that everyone should be tested, not only those who come to the health services, which is probably likely to happen in practice. People who come to the health services are predominantly women. If women are the ones who are going to be tested mandatorily, then what are the gender consequences for them? We live in a country with very high levels of violence, including intimate partner violence. Women are going to go home with an HIV-positive result and are likely to disclose to their partner before their (male) partner does. We will have to provide all the necessary counselling and support—an aspect which has not been very clearly thought through.

#### 4. What is the human rights burden and benefit from this policy?

The human rights burden is not just about privacy and bodily integrity. HIV is different from other diseases. Gugu Dlamini<sup>20</sup> died as a result of her HIV-status and other women have also suffered as a result of their HIV-positive status. The human rights burden is also about physical and other kinds of violence and being displaced from the home. We might think that mandatory may help solve the problem, but it may create other problems.

There are benefits in terms of access to care and the decrease in transmission, but these benefits are not absolute and need to be balanced against other harms.

#### 5. Is there anything less restrictive that can be implemented to achieve this?

There are other measures that could encourage more people to be tested for HIV such as getting our political leaders, celebrities and sports stars to create a culture of testing for HIV in South Africa.

While the objective of trying to increase the number of people who know their status and who are on treatment is cogent, there are other ways of increasing testing uptake that would be less restrictive than mandatory testing. I do not think we can justify introducing mandatory testing. I think that if we were to introduce it, it would negatively discriminate against women.

In closing, London argued that that the situation is desperate, but we need to guard against grabbing onto a desperate solution that might be worse than the problem.

### Public health realities: A health manager's perspective

Dr Janet Giddy argued that HIV testing should no longer be 'exceptionalised,21'

Giddy questioned the reasons in HIV being "exceptionalised". Proffering her view, Giddy said: "It has to do with the history of HIV over the last thirty years—there was enormous stigma, the long latency period<sup>22</sup> of HIV which silently erodes the immune system while people are well, the spread of the disease to many partners, the fact that it is mostly transmitted during intimate contact between adults in private, the fact initially there was no treatment and the very high fatality rate."

"We really need to treat HIV as a normal disease in order to counteract the stigma surrounding the virus and to encourage people to get tested and to seek treatment timeously.23"

According to Judge Edwin Cameron, both the world and the HIV epidemic have changed. The elaborate protections (such as the need for consent to be tested to be provided voluntarily) around the disease were designed for a time when stigma caused death and from when people needed to be protected from unnecessary HIV testing (due to a lack of treatment) which often caused victimisation, ostracism and discrimination. Now that treatment is available and HIV is medically manageable and not fatal, HIV should be treated like any other normal disease such as malaria. In Cameron's view, the testing safeguards around HIV hampered the successful management of the disease and actually contributed to stigma.

"People fear getting testing for HIV, but we as healthcare providers have added to that fear and anxiety because we treat HIV testing as such a rigmarole. There is no other test where one needs to go through pre- and postcounselling sessions and have signed consent. All of this accentuates the differentness, distinction and horror of AIDS and emphasises to the patient that this disease is exceptional, abnormal and unusual," said Dr Giddy.

Dr Giddy outlined two procedures that were simultaneously taking place in South Africa:

- Firstly, there is client-initiated testing (previously known as VCT), where the client takes the initiative and actively seeks to be tested for HIV and agree to be tested.
- The alternative is provider-initiated testing where healthcare workers routinely offer HIV-testing to all clients. Patients either opt-in by consenting to the test, or opt out by explicitly declining to be tested, after pre-test information is provided.

To argue her point, Dr Giddy referred to an opt-out study that was performed by her team at the McCord Hospital antenatal clinic to prevent mother-to-child transmission of HIV:

"As part of normal care, women and/or their partners would be given information about HIV as part of the routine information session about antenatal care. All their blood tests were done at the same time, unless they specifically refused.

The opt-out testing increased the uptake of HIV testing from 88% to 99%. An evaluation of the staff and patients perceptions about the acceptability of this testing method was very positive. It improved efficiency in the clinic, as it went much more quickly because we did not have to send everyone via the counsellors. There were also no adverse patient responses.

Another benefit was that our prevalence increased as women who would have refused to test before, were now testing - they were often the women who had HIV. The staff were initially very sceptical and nervous, but after the study, they adopted it as a standard of care. Five years later, we cannot believe that it has worked so well and hasn't been adopted on a wide scale across South Africa."

Concluding her argument, Giddy said there should be a move towards viewing HIV as a common chronic disease that needs to be normalised. She added, testing should be done in an uncomplicated way using opt-

<sup>&</sup>lt;sup>20</sup>A woman who was stoned to death after community members in KZN discovered she was HIV positive

<sup>&</sup>lt;sup>2</sup>'According to Dr Giddy, this refers the tendency to treat HIV as different from other diseases through processes such as pre- and post- counselling <sup>22</sup>The period of time between HIV infection and the onset of symptoms

<sup>&</sup>lt;sup>23</sup>Judge Edwin Cameron at the Ronald Louw Memorial lecture, Ronald Louw being a person who died of AIDS, two weeks after testing for HIV having after refusing to be tested

out testing. Giddy also advised that there still needs to be respect for confidentiality and that greater work needs to be done on official ethical and legal guidelines to support this approach via the Health Practitioners Council of South Africa.



### **Discussion and Comments from the Floor**

COMMENT 1: 'Has an opportunity been lost with the Strategic Plan for HIV (NSP)? It implied that we should have opt-out testing but we are calling it HIV Counselling and Testing (HCT) and we try to get everyone in South Africa to be tested, but there is no real call for opt-out testing, like in Bostwana. Why not a bigger push in South Africa for the opt-out testing or wellness screening?'

- **JG:** When they were drawing up the most recent national guidelines, we made a very strong push to make opt-out testing as part of the prevention-of-mother-to-child guidelines at least. It was considered too controversial, with much anxiety around human rights.
- **LL:** In opt-out testing people are still giving consent, even if it is not written consent. There is still a degree of permission and autonomy. It is completely different from mandatory testing.

COMMENT 2: 'How is this testing going to be done, when we know that the window period is the most infectious period? How often would people need to be tested?'

**GvC:** If we look at the Test and Treat approach, you would need to test everyone at least once a year, and ideally if you want this to work perfectly, you need to test even more frequently to catch people within the window period or just after the window period when they are most infectious.

COMMENT 3: 'I would like to raise two points that have not been raised in this debate. We have failed with the TB epidemic and putting people onto treatment. Ronald [Louw] died because of undetected TB. He was on treatment— he was an activist with the Treatment Action Campaign (TAC) and that was the real tragedy of his death. I think our estimates are that more than 4 000 people are still dying of TB daily, a preventable disease and we are not winning that battle. So there is a critical argument to medicalise this and to ensure that we save the lives of people living with TB and infectious diseases.

The other thing that we need to talk about is patient empowerment, which TAC has pioneered in terms of treatment literacy.

COMMENT 4: 'I am from the TAC in Khayelitsha. We have seen so many people die in Khayelitsha, even the ones who are aware about their disease and the treatment they are taking. Not because they do not want to take their treatment or do not want to test for HIV, but because of the socio-economic conditions that they live under. This is a subject that I have not heard any of our speakers touch on some of the challenges that patients face.'

LL: That question illustrates that we have a health system that is struggling. We cannot look at this problem and think that we are going to solve it through mandatory testing. The TB epidemic is what it is, not because we are not testing people, but because we are not tracing contacts, we are not keeping patients in care, we are not practicing proper infection control—we are not getting the basics right. The reasons people do not want to come forward to get tested and struggle with treatment because of the conditions they live in— they do not have food, a job. We cannot solve the problem of drug stock outs or rude staff through mandatory testing. It is not that we should not increase the number of people to get tested, but we need to solve the health system problems at fundamental level, because that is where the problem lies.

PR: There are other challenges that we are faced with, but these should not stop a person from knowing their status. For us to take ARVs we need food. If I take my Stocrin without food, my stomach is going to burn all night, but I can take Stocrin with a slice of bread and it will not bother me. We should not try to create a reason for people not to get tested. I feel like for the past thirty years we have been coming up with reasons for people to test and it is time we stop doing that.

COMMENT 5: 'Nobody has defined what mandatory testing is. Mandatory testing means officially required. When we talk about mandatory testing, are we talking about the opt-out option, or what is it we are actually talking about?'

- **LL:** I think we have made it quite clear that nobody knows what mandatory testing would imply. The Democratic Alliance once called for everyone needing an HIV test if they get married—that would be one example of mandatory testing.
- **JG:** I think that there are places where it has been used which may be controversial, such as the military. There have also been some suggestions made, such as if you want to enter into high risk professions, such as being a nurse, it is better to know your status and can be used to control for whether you can enter that profession.

I think that what people mean when they talk about mandatory testing is getting some way of forcing the whole population to test. It is coercive in its nature.

COMMENT 6: 'Is a person's response to an HIV test that they would not have done voluntarily different from their response to an HIV test that they would do voluntarily? I think that the assumption of us that those of us who believe we should push hard and go as far as mandatory testing, is that yes they would still benefit and change behaviour in the same way that someone who voluntarily does the HIV test. How is it that we can test the assumption that a forced HIV test is not a useful test in terms of behaviour change?'

**JG:** We have done an interesting study as to how people link to care after HIV test. We found that one of the reasons that people were not linked to care was if they were referred by the provider as opposed to the people who come forward to get tested of themselves.

COMMENT 7: 'In terms of our current human resource shortages, do we have the capacity to deal with the people who will come forward for testing? There is also the issue of loss to follow up of the new patients who will come forward to be tested, when we are already not coping with those who already know their status.'

**PR**: At the moment we do not have the capacity but we have been talking about this for the past ten years. There is a lot of talk about developing the capacity and infrastructure for this country to be able to meet the demand. We know that when we go to a hospital today, we have hundreds of patients with AIDS. Why should we have those patients there, whereas we could be testing and treating them?

COMMENT 8: 'If one of the barriers to HIV testing is the stigma around it, is it not worth a risk of a small infringement on human rights to attempt to quell stigma by doing mandatory testing?'

LL: Even if you were to introduce mandatory testing, I don't think it would address the problem of stigma unless you introduced a whole lot of other things such as high level leadership...education at schools, addressing gender based violence and many other things. Once you have done that, you might find that you might not need mandatory testing. There are other ways of routinizing HIV testing. The fixation on mandatory testing is the wrong end of the problem. We need to deal with stigma. We have a very unfortunate history of bad handling of HIV way back from the apartheid days which has entrenched its view as a black disease, a poor disease and moralistic views. We have a long way to go to undo that, but there are ways to do it.

## Conclusion and closing remarks

- GvC: We need to reduce the barriers to testing. We need to integrate routine, normalised testing into all the possible settings. For every person who is seeing patients, we need to be proposing HIV testing. We need to bring testing to the people and to move closer to community-based testing because only testing in facilities is not going to do it.
- PR: We should not say mandatory testing will not work before we test it. We are creating so many barriers around HIV that is encouraging a lot of people to be ashamed of living with HIV. We have to start normalising HIV by making sure that everyone knows their status. We should not encourage shame because that is what keeps people hiding. For us to have everyone tested, we have to make sure that any person who should know their status, do so, whether by choice or not. I think we should force people to test, as the reason that people are not testing because of the shame that is being encouraged.
- LL: If we talk about mandatory testing, we cannot do so in isolation from looking at the health system. The health system needs fixing and that question of mandatory testing needs to fit into that. In the Western Cape we have decreased our HIV transmission from mother to child to 2% and we have not done that based on mandatory testing but through VCT. So we can do it if we fix the system.
  - We can relax the system around testing but we have to think through very carefully how it works. We have to make sure that the person does not suffer ostracism and it is a very tough call on the health worker to know if that will happen. So there is a lot we have to learn about how we make that work.
- JG: We need to improve the policies around HIV testing. There is quite a lot of confusion, uncertainty and anxiety around who does what and how.
  - We need to simplify the processes and integrate it into care. There are many missed opportunities to test because of all this confusion.





www.msf.org.za



www.shawco.org