



Not ‘the end of AIDS’ – Moving from Quantity to Quality in Order to Sustain the Results of Global AIDS Activism:

- **A look at the reality of HIV/AIDS in South Africa, December 2012,**
- **Substantial progress has been made but serious problems threaten success**

Speech to:

- Oxford University Student HIV/AIDS Research day, 26 November 2012;
- European Parliament working group on Reproductive Health, HIV/AIDS and Development; and on Innovation, Access to Medicines and Poverty Related Diseases, 28 November, 2012;

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According to UNAIDS on World AIDS Day 2012 for the first time we can celebrate the possibility of the eradication of HIV and therefore the end of AIDS in the foreseeable future. In the words of Michel Sidibé, executive director of UNAIDS:

“The pace of progress is quickening - what used to take a decade is now being achieved in 24 months .. We are scaling-up faster and smarter than ever before. It is proof that with political will and follow through we can reach our shared goals by 2015.”

Elsewhere it is stated:

“The evidence gathered from countries around the world tell a story of clear success.”

And:

“A new era of hope has emerged in countries and communities across the world that had previously been devastated by AIDS”.

Thus, UNAIDS believes, there is a “genuine opportunity to plan for the end of AIDS” albeit that “a significant additional effort is required” and there remain what are vaguely termed “challenges”.¹

¹ This idea is echoed by other parts of the UN bureaucracy who seem to be working from the same script. For example, the Executive Summary to the report of the Global Commission on HIV and the Law (July 2012) begins as follows: “The end of the global AIDS epidemic is within our reach. This will only be possible if science and action are accompanied by a tangible commitment to respecting human dignity and ending injustice.”

The aim of my lecture today is to interrogate whether such a rosy view can really be taken of the HIV/AIDS epidemic. I do so mainly by looking at what is happening in South Africa, a country that is said to have a 'generalised, predominantly heterosexual' epidemic and which is still home to almost a quarter of the world's HIV infections – 5.1 million people according to UNAIDS.

But South Africa is also a country that in some ways represents the world of the AIDS epidemic: it hosts most of the globe's sub-epidemics (separate epidemics exist among men who have sex with Men (MSM), sex workers, drug users and other groups horribly termed MARPS (most at risk populations). Each of these epidemics has its own story to tell about whether we are succeeding, or not, in controlling HIV.

Substantial Progress?

There is no doubting that in the last decade there has been significant progress.

According to UNAIDS, by the end of 2011, 8 million people in low- and middle-income countries were receiving antiretroviral treatment - a 20-fold increase since 2005.

In South Africa, according to Dr Thobile Mbengashe, the head of the ARV programme, over two million people have been enrolled onto ARVs since the start of the epidemic. "The number of new HIV patients started on treatment in 2010/11 was 631,000. The target for the year was 625,000. The number of patients who are currently on treatment is 1,7 million."²

To do this has required first of all political commitment to HIV treatment from the government. With such commitment there has been a massive expansion of points of access to ARVs, achieved by doing away with the restrictive system of accreditation imposed by Manto Tshabalala-Msimang, the former Minister of Health, thereby allowing more than 4,000 clinics and hospitals to prescribe ARVs.

In some respects the results have been quite dramatic. Vertical transmission of HIV is now reportedly under 2,5% at six weeks post partum, down from 25-30% a decade ago.³

As a result there has been a reduction in infant and under-five mortality. For example, last week it was reported in the media that Cotlands Baby Sanctuary was closing its AIDS hospice. In 2002, 87 babies at Cotlands died of HIV; for the last three years there have been no child deaths. Cotlands was an amicus curiae in the famous TAC case, so the symbolism of this is huge.

In addition because so many people are taking ARVs, there has been a rise in adult life expectancy to nearly 60, when at the peak of the epidemic life expectancy had dropped to just above 50 - in the face of an estimated 1,000 HIV related deaths per day.

In the technology of HIV prevention there has also been progress. There now exists an armoury of interventions for combination HIV prevention: condoms, medical male circumcision, post and pre exposure ARV prophylaxis, and not too far away, microbicides. We also know of the preventative benefit of ARVs. The problem, however, is that human behaviour remains stubborn and complex and the take up of HIV prevention cannot be demonstrated with the same confidence that we have seen the take up of ARV treatment.

² Private communication, Dr Thobile Mbengashe, 14 September 2012.

³ Medical Research Council (MRC).

So the picture does indeed seem rosy. Or does it?

Serious problems?

In South Africa, as in the world, great strides have been made. The 2012 AIDS landscape is unrecognisable from that of 2000, when global activists led by TAC staged the first global march for treatment at the international AIDS Conference, held for the first time in Africa. But my argument is that because (most) governments and the United Nations have paid insufficient attention to the quality of HIV prevention and treatment programmes, dynamite has been built into the edifice of the AIDS response – and the clock is ticking.

In many countries' AIDS response – including those pivotal to the future of the AIDS epidemic, such as SA and China - there is a dearth of qualitative information/evidence about patient retention, drug adherence, adverse effects, discrimination and human rights violations. Another factor that needs to be considered - especially in South Africa –is the effect of collapsing public health systems on the ARV programme. In this respect, the biggest cause for concern is not the evidence we have, but the evidence we don't have. As a result we have to rely on anecdote. But what we hear and see anecdotally is not good.

Here are two examples:

With so many people either on treatment or awaiting treatment high patient retention is essential. Are we succeeding with this? Dr Francois Venter, former President of the HIV Clinicians Society and one of South Africa's leading HIV clinicians, puts it like this:

I am scared.

Initially, our retention was superb – and now I worry it seems to be falling down a bit; programmes are becoming a bit easy-going.

Has to do with poor M&E and follow-up systems and attention to social issues – also, the recurrent drug stock outs undermine patient confidence in the system.

As 'integration' has occurred (as it should) – people now see the real face of health care, which is not the friendly happy HIV-motivated docs and staff of the past....⁴

On a more scientific basis, a meta-analysis by Rosen and Fox⁵, where most of the studies analysed were drawn from South Africa, points to huge gaps in the information that is available about retention. Nonetheless the authors are able to draw certain conclusions and the results are not good, particularly if viewed in the context of South Africa's 2010-2011 HIV Counselling and Testing (HCT) campaign which resulted in more than 15 million people voluntarily testing for HIV.⁶ The study's authors point out that it "is not possible with the data available" to answer the question

⁴ Personal e-mail, Dr Francois Venter, 25 November 2012.

⁵ Rosen S, Fox MP (2011) Retention in HIV Care between Testing and Treatment in Sub-Saharan Africa: A Systematic Review. PLoS Med 8(7): e1001056. <http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001056>

⁶ See: Implementation Status of the HCT Campaign and ART Expansion Programme, Achievements, Challenges and Lessons Learn, April 2010-June 2011, 'A joint report by the Department of Health, SANAC, UN Agencies and development partners', draft 3, Nov 2011. As far as I know this report has not been published. It is also worth noting that there has not been a peer reviewed report on the HCT campaign, or even any serious attempt to analyse the data that it generated.

“what proportion of patients who test positive for HIV are staged, enrol and remain in pre-ART care until ART eligibility, and initiate ART.” They go on:

“Only a handful of countries are represented, and most by no more than one or two studies. No study provides all the information needed to answer this question, even for a single setting, and combining results from multiple studies appears ill-advised. To examine the implications of doing this, we multiplied the median proportions of patients achieving the study end point in each stage (Stage 1, 59%; Stage 2, 46%; Stage 3, 68%), and found that the information available suggests that only about 18% of patients who are not yet eligible for ART when they are diagnosed with HIV remain continuously in care until ART eligibility.”

The Fox/Rosen study takes analyses patient retention up to the point where people are initiated onto ARV treatment. But what do we know about adherence after initiation on treatment? Again, there is little hard evidence, particularly in the period since the dramatic scale-up of access to ART. Thus, we should warn that although the oft cited 2006 meta-analysis by Mills et al showed higher rates of ‘adequate adherence’ in Southern Africa (77%) than in North America (55%),⁷ it cannot be assumed that this will remain the case forever, or that it has remained the case. The context was vastly different.

For example, in real life I am aware of two major challenges to adherence, neither of which can be blamed on the patient him or herself. These are:

- (a) The impact of collapsing health systems on people’s ability to obtain their prescribed medicines, and
- (b) The absence of publicly financed health messaging promoting and explaining the need for adherence.

As an example of the former consider the following real-time scenario.

The O R Tambo district of the Eastern Cape is one of the poorest districts in South Africa. It is home to 1,8 million people, has an HIV prevalence of 23%, and by June 2012 an estimated 40,000 people on treatment. As a demonstration that poverty need not be associated with failure, it is worth recalling that it was in Lusikisiki in the OR Tambo district that the feasibility of rural ARV treatment programmes was first demonstrated by Medecins Sans Frontieres (MSF) and TAC.⁸

Today, however, it’s a different story. Real world problems have risen to the fore. In this district one of the biggest problems lies in the fact that all medicines are supplied through a depot in Umtata, where according Noloyiso Ntamenthlo of TAC:

“there is lot of corruption, always a shortage of treatment which affects the clinics and the hospital, a shortage of staff and there is a difference between the Port Elizabeth (PE) service users and OR Tambo; at PE they get 3 months or 2 months [of medicines] but in OR Tambo

⁷ Mills EJ, Nachega JB, Bangsberg DR, Singh S, Rachlis B, et al. (2006) Adherence to HAART: A Systematic Review of Developed and Developing Nation Patient-Reported Barriers and Facilitators. PLoS Med 3(11): e438. doi:10.1371/journal.pmed.0030438

⁸ N. Ford et al, Sustainability of Long Term Treatment in a Rural District: the Lusikisiki model of decentralised HIV/AIDS care, Southern African Journal of Medicine, December 2006.

they get 1 month or 2 weeks or 3 day supply. OR Tambo pharmacists say they are struggling to get their full supply, instead of full supply they always get half of treatment.”⁹

We do not know the consequence of this situation on adherence. But given that this is a rural area where people walk many kilometres to clinics to get their medicines, or pay for taxis in households with almost no money, it cannot be good.

One possible indicator is the worryingly high level of virological failure amongst patients taking ARVs detected by MSF in Mbongolwane and Eshowe, KwaZulu Natal, in the course of collecting routine programmatic data on the ARV programme and its outcomes in the area.¹⁰ MSF has alerted district and provincial health authorities of its findings, but predictably there appears to have been no action. My guess, however, is that there is little that distinguishes the social environment of Lusikisiki from that of Eshowe; background virological failure may well be similar in similar districts. One way to avoid the need to guess would be for the National Health Laboratory Services (NHLS) to analyse and make public the hundreds of thousands of viral load tests they hold in their database. From such a report we would gain a far more accurate picture of predictive indicators of HIV treatment.

A second issue of concern is the issue of optimal drug regimens and the side-effects associated with the continued use of sub-optimal and for some people unsafe medicines.

For the vast majority of people on ARVs in SA side-effect are not an issue. But with an ARV programme as big as ours that does not mean that we should not be concerned with a minority who do suffer these problems. In this respect, from time to time the media has played an unhelpful role in sensationalising ARV related side-effects, particularly lipodystrophy. This has caused alarm, stigma and some fear. But unfortunately, the fact that the promised pharmacovigilance centre was never set up, means that again we have little quantitative or qualitative information to go on. But anecdote is cause enough for concern.

Last week, for example, Edwin Cameron reported to me that:

“At a World AIDS Day talk I gave (at a big bank), several people, who seemed well-informed carers and field-workers, raised the problem of body-fat mal-distributions (lipodystrophy).

This took me by surprise: it's the first time I have ever heard this problem raised in regard to our mass ARV roll-out. I asked which drugs, and was told, Combivir. I thought Truvada had become first-line, but it seems not. My informants claimed this had become a big problem with treatment initiation and with drug adherence.”¹¹

In response to this e-mail Nathan Geffen, an experienced and knowledgeable commentator on HIV science, stated:

“Hundreds of thousands of people are still on stavudine (d4t) and I suspect that in the public health system many health workers don't see lipo as a big enough side effect to warrant a regimen change, or they're reluctant to switch people to Tenofovir (TDF) for some other reasons. Of course lipo is an awful side-effect. It's probably not life-threatening (at least in

⁹ Private communication, Noloyiso Ntamenthlo, 25th November 2012.

¹⁰ Private communication, Dr Gilles van Cutsem, MSF Head of Mission, 27 November 2012.

¹¹ Private communication, Justice Edwin Cameron, 22 November 2012.

the short-term) but it's psychologically terrible and patients should be taken of d4T or AZT when they have symptoms of it.”¹²

SA took the decision to phase out d4T more than two years ago, but it is clearly still widely prescribed. A similar situation exists in other sub-Saharan countries.

It is realities such as these which in my view make it naive, if not downright irresponsible, to talk of ‘the end of AIDS’.

What about Human rights and civil society mobilisation?

Two of the most distinguishing and important features of the global response to HIV have been community mobilisation and the demand that all human rights be protected and promoted in the response to AIDS. Without social mobilisation of hundreds of thousands of activists, independent of UNAIDS, UNAIDS would not have been able to mount the pretence about ‘the end of AIDS.’ Without the conviction that access to treatment is a human right it would not have been possible for activists to mobilise their societies and to force the emergence of political commitment at a governmental level. However, as we go into 2013, both social mobilisation and respect for fundamental human rights approach are being threatened – and UNAIDS is strangely silent about both.

Earlier this year, Dr Shereen El Feki, the chairperson of the Global Commission on HIV and the Law, wrote that “I would like to think that 2012 represents a turning point in how we look at the impact of law on the global epidemic.” El Feki rather naively takes comfort in the umpteenth political commitment by government leaders to respect human rights, saying:

“a recent commitment by Commonwealth Foreign Ministers—whose countries account for almost a third of the world's population and some of the most repressive legislation on the planet when it comes to HIV—to work towards repealing discriminatory laws that hamper their response to the epidemic, sets an encouraging course for the years to come.”

However, the lived experience of people on the ground, particularly people who UNAIDS with its warped love of turning people into acronyms calls MARPS, does not justify such faith.

Again, a few examples drawn from South Africa may serve as illustration.

In KwaZulu Natal (KZN), the province with the highest incidence and prevalence of HIV - above 40% in some districts — an unknown number of boys and men are getting their penis’s mangled by a device known as the TaraKLamp, which is being widely used for ‘voluntary’ male circumcision. This device was found to be unsafe in a randomised trial at the same site in South Africa that demonstrated, along with two other trials, the efficacy of male circumcision in HIV prevention. The Tara KLamp's use was stopped because it caused much higher adverse events than surgical circumcision.

Nonetheless, the Provincial Health Department in KZN – supported by the Premiere of the Province - has elected to use this device, despite fierce criticism from TAC, as well as the fact that the Minister of Health is not recommending its use in VMMC programmes in any of South Africa’s other eight provinces. There is mounting evidence (admittedly anecdotal and not properly recorded) of the

¹² Private communication, Nathan Geffen, 22 November 2012.

harm it is causing. This is best described in an internal TAC e-mail, copied in the footnote below.¹³ In addition, there are reports that young men and boys are being herded into circumcision camps where there is no notion of proper consent.

Ironically, human rights are now being violated in the name of the human right to life and treatment. In KZN the provincial health department carries out the VMMC programme in league with traditional leaders who are conducting the campaign because it is sanctioned and ordered by the King. The idea that the Zulu King's subjects have rights to dignity, autonomy, informed consent or safe medical practice seems to be an alien one. Civil society has been powerless to stop this assault.¹⁴ The WHO and UNAIDS, despite being well aware of this issue, have been deafeningly silent. Why?

Dr El Feki admits that "the reality is that change takes time, particularly when laws, and law enforcement, are influenced by conservative currents and selective interpretations of religion and tradition." However, she does not take the next step and point out that the most effective counter to bad laws is good civil society. Instead she has "hope that as more evidence of the impact of laws comes to light, and more voices are brought to calls for reform, the tide is slowly shifting towards a more tolerant, pragmatic, and just legal environment for all whose lives are touched by HIV."¹⁵ There is no science to support 'hope'. That is more a matter for prayer. However, I would argue that without activism such hope is ill-founded.

Unfortunately, AIDS activism is another area where there is a dangerous regression. From the earliest days of the AIDS epidemic the pace of development of medicines, human rights protection

¹³ E-mail report on use of TaraKlamp in a district in KZN: "RS received an urgent call from TAC members of uThungulu district (Mabuyeni branch) because of the serious circumcision complications. The community of uThungulu district eMabuyeni is in a serious crisis of TaraKlamp male circumcision that was done by the DOH on the 13th- 14th October 2012 at eMabuyeni Tribal Court. On the 25th October 2012, Thursday he visited eMabuyeni community including some of the families. During his arrival I managed to meet some of young boys and all of them are in a serious condition after they have been circumcised in a past two weeks. One of the young boys, who is 10 years old, his mother did not receive consent form to sign for her son. Most of the boys suffered from bad wounds in their private parts, blisters, one of the boys had external bleeding almost 3 days non-stop after circumcised with Tara Klamp he end up admitted to Ngwelezane hospital. During the boys' complications the parents requested the transport from local clinic for medical check up and other diagnosis, but the response from Ngwelezane hospital was to say no ambulance or transport is available at that time, the parent should get transport in their own. Therefore the parents suffered and struggled to bring their children at Ngwelezane Hospital because most of the parents are unemployed it was difficult for them to hire meter Taxi. During the circumcision process HIV testing was done to everyone before circumcision starts, but the remaining question is that to all those who went for HIV test no one was found to be unfit to circumcised after HIV testing.

The next day (Friday 27 October 2012) I also went to visit eMabuyeni Junior Secondary School, it's where most of the Circumcised boys are. I managed to meet school HOD Miss Mhlongo because the school principal was not in the office. Miss Mhlongo informed me that after the circumcision the school is facing the huge challenge such as:

- High rate of boys being absent from school;
- Boys seating complications in the classroom, they need to sit and open their legs because of the pain they feel
- Regular out of the classrooms because they need to go and drink water, sometimes you found them standing outside toilets holding the side of their private parts because of the pains they feel
- Some are using various walking sticks to accommodate their complications

During my visit the HOD said almost 30 boys were absent from school because of pains. The entire school management is worried about this condition because it affects the normal learning process.

My own assessment in this matter, amongst all the stories and comments from the community it was clear they are not happy about this circumcision using TaraKlamp.

A young boys of 10 years because of the circumcision complications that he suffered, is now treating everyone who visit his home as a stranger who comes in to touch his private part. He always run away and hide himself, for me these are the trauma indications.

I even phoned Dr Tshabalala from DOH (the provincial Circumcision manager) reporting the situation that in front of me I'm with the boys, who are suffering almost 3 weeks after Circumcision by Tara Klamp.

It also alleged that this also applies to the area of kwa-Dlangezwa under INkosi Mkhwanazi is the very same issue.

¹⁴ For background on the TaraKlamp see:

<http://www.quackdown.info/article/tara-klamp-story-update/>; TAC's Complaint to the Public Protector:

<http://www.tac.org.za/userfiles/Affidavit%283%29.pdf>; A webpage with the above complaint and annexures is here:

<http://www.quackdown.info/article/tac-complains-public-protector-about-tara-klamp/>.

¹⁵ Dr Shereen El Feki, 'In the balance - HIV and the law', <http://www.hivlawcommission.org/index.php/media-center/updates/134-in-the-balance-hiv-and-the-law>

and political will was driven by civil society, and particularly by vociferous and activist organisations of people living with HIV, such as ACT-UP, the Gay Men's Health Crisis and later TAC. The rising expenditure in HIV generated by activism saw rising funding for organisations of activists, such as TAC. But over time this created a donor dependence, particularly in developing countries, and now that donors are turning their backs on HIV, they are also turning their backs on these organisations, thereby strangling the civil society response.

Again, it is noteworthy that despite civil society being considered a 'critical enabler' in the UNAIDS Investment Strategy, there seems to be no strategy to sustain civil society or to advocate for its funding. In this context it has to be debated whether organisations like the UNDP and UNAIDS, which spend millions of dollars on their various HIV-related 'commissions' would not have been better advised to make a similar amount of money available to organisations that truly have the capacity to alter the epidemic curve.

Funding to the finish line

The idea of 'the end of AIDS' seems to be partly premised on a deceit. The deceit is this: first, to show that UNAIDS has made a difference (which it undoubtedly has, although perhaps not the difference donor countries seek); and second to suggest that with one big push we will cross the finishing line. This is just not true. As I have tried to show in this paper, we are far from the end of AIDS, neither can we minimise the costs that will really be required to consolidate and entrench the remarkable gains that the world has actually made in a relatively short time in its efforts to prevent and treat HIV.

Consider just the following facts:

- At a global level 6.8 million people - nearly half of those eligible - still do not have access to ARVs. According to UNAIDS "Half will die within 24 months if they don't start antiretroviral therapy". Getting treatment to these seven million people is not just a question of steadily expanded access, because the people not yet in the treatment pool and often the people outside the social pool ie. people who are marginalised and/or criminalised. To secure health rights for these people needs much more than just the cost of medicines; it requires social transformation and expenditure on human rights.
- International and domestic funding needs to increase. But the reverse is happening. Although there has been an improvement in domestic expenditure on AIDS, international spending still accounted for more than half of spending in 59 countries and contributed more than 75 percent of spending in 43 of the 102 low- and middle-income countries. In the context of economic recession and stagnation this picture is unlikely to improve.

Conclusion: the end of (global political commitment to) AIDS?

In South Africa in 2012 politics has been dominated by evidence of the crisis in public education. Universal access to education, a major achievement of the ANC post-apartheid, has not been accompanied by a consonant rise in the quality of education. As a result outcomes are deteriorating. There is a parallel to be drawn here.

If expanded access to ARVs is not accompanied by an improved quality of care, ultimately the object of access, life and dignity, will be defeated.

In late 2012, three years into the Zuma Presidency, the ARV programme is one of the few matters about which the Zuma administration can boast. But it is becoming clearer that improved access may be associated with a deteriorating quality of care. This is not – as conservative public health experts would argue - because expanding access automatically undermines quality, it does not. Rather it is because there has not been a political commitment in parts of the government beyond or out of the control of the Minister of Health, to ensure that access is accompanied by quality. As with so many things in SA, it's a superficial numbers game – not a dignity and equality game.

All this makes UNAIDS hype of 2012 as a watershed moment feel hollow and negligently simplistic. What we are beginning to detect is not the type of watershed that UNAIDS seems want us to believe in, but possibly its opposite. The human rights of people with HIV/AIDS are losing the battle to complacency, developed country self-interest and a recession of convenience that allows a redirection of aid away from AIDS. In reality, it might be said that rather than being elevated the response to AIDS is being relegated to a level more akin with the response normally accorded to third world diseases such as TB.

ENDS