TREATMENT ACTION CAMPAIGN

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Submission to African Peer Review Mechanism

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The HIV Epidemic: A discussion of the response of the South African Government

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Work of the Treatment Action Campaign

The Treatment Action Campaign (TAC) is a non-profit organisation and movement of people living with HIV/AIDS that was launched on 10 December 1998. Its main objective is to campaign for greater access to HIV treatment for all South Africans, by raising public awareness and understanding about issues surrounding the availability, affordability and use of HIV treatments. TAC has been outspoken on government's responsibility to respond to the HIV epidemic, and, at times, its apparent unwillingness and inability to do so appropriately. TAC has also campaigned against certain practices of pharmaceutical companies, including excessive pricing, unethical marketing practices and unethical clinical trials. In addition to this campaigning role, TAC provides HIV/AIDS services to communities by conducting HIV education (including treatment, prevention and nutrition with respect to the HIV epidemic), facilitating and sponsoring treatment provision, mobilising communities to take action on HIV, and assisting individuals to get tested and treated for HIV.

TAC has a national office, six provincial offices and a number of district offices, it employs 62 people and has a membership of approximately 16,000 people, a majority of whom are low-income African women, most of whom are unemployed. We have about 200 volunteer-driven branches. Our membership is mostly made up of people living with HIV, but includes people from diverse backgrounds, including doctors, nurses, researchers, academics and workers.

Recommendations

TAC recommends the following actions for government to alleviate the HIV epidemic:

- **Public Relations, Education and Prevention**
    - Improve public messaging. The President and the Minister of Health unequivocally have to state that HIV causes AIDS, encourage people to get tested, if necessary get treated and to practise safer sex by using condoms.
    - Produce, or adopt, an accurate fact sheet on nutrition aimed at the general public. The Minister of Health must begin to provide accurate information on nutrition and HIV.
    1. Promote condom distribution in schools and all areas of community life. Take steps to reduce the cost of the female condom so that distribution can be increased. Significantly increase condom promotion.
    - Provide a new improved HIV prevention plan and strengthen the research agenda in respect of prevention.
- **The Health Sector and Human Resources**

- Through a consultative process, produce a human resources plan and take immediate steps to improve conditions of service in the health system.
- Reduce the inequality in health-care between the well-off and the poor by beginning the process of establishing a single unified health-care system with universal access.

Medicines

- Allow and encourage health facilities to replace the single-dose nevirapine regimen for reducing mother-to-child transmission transmission with a more optimal regimen, such as the AZT plus single-dose nevirapine regimen used in the Western Cape, or the even more effective regimens which are likely to eradicate the paediatric HIV epidemic. These newer and more effective regimens have been implemented with success in the United States and Brazil and could be rolled out in South Africa. This should be done wherever possible, even if certain regions continue on existing regimens until infrastructure improves; equity does not demand that we equalise down.
- Provide fluconazole and acyclovir, medicines used to treat opportunistic infections[1], to all health facilities. Reduce the schedule of donated fluconazole so that nurses can dispense it more easily.[2]
- Standardise the vitamin regimen offered to people with HIV in the public sector so that it consists of the same constituents used in the effective arm in the Tanzanian multivitamin study (Fawzi *et al.,* NEJM Volume 351:23-32, July 1, 2004 Number 1).

Governance

- Take steps to meet the original antiretroviral treatment targets of the Operational Plan. Alternatively, if the slow start has rendered the interim targets unattainable, these should be revised, with the ultimate target of universal rollout being kept in place. In any case, this would include establishing monitoring and evaluation mechanisms for the antiretroviral sites and running a media campaign to encourage people to get tested and, if necessary, treated, increasing the resources at antiretroviral sites, especially the number of health workers as envisaged in the Operational Plan. Voluntary counselling and testing needs to be standardised across clinics and must include an explanation of safer sex and condom distribution. Routine offer and active promotion of testing for HIV should be introduced at public health facilities. Integrate the management of TB and HIV.

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1 Fluconazole treats system thrush and cryptococcal meningitis. Acyclovir treats herpes.

2 Fluconazole donated by Pfizer has a higher schedule than before it was donated in order to protect Pfizer's interests. But this makes it more difficult for nurses to ensure their patients obtain this essential medicine.

- Investigate addressing the catch-22 situation faced by people with HIV accessing the disability grant who need to choose between the grant and antiretroviral treatment. We acknowledge this is a complex issue. A universal social grant, such as the Basic Income Grant, and/or a massive scale-up of public works might contribute to alleviating this dilemna.
- Be prepared to work with the TAC and civil society bodies that are critical of government.
- Ensure that important institutions such as the MCC and the MRC maintain their independence and are provided with appropriate budgets to do their work.
- Create, implement and review policies based on scientific evidence gathered from the best available sources.
- Complete the access to medicines framework.
- Draw up a Health Charter.

HIV epidemic in SA

South Africa possibly has more people living with HIV than any other country. If not, then South Africa is second only to India. Various estimates of the number of infected people have been made by the Department of Health, the Actuarial Society of South Africa, the Human Science Research Council and Statistics SA. These range from 4.5 to 6.3 million people living with HIV. We cannot be sure which estimate is the most accurate, particularly as modelling and survey-based approaches have been used, but there is consensus that the epidemic is large.

Based on the antenatal clinic results and the HSRC household survey, young women and girls between the ages of 25 to 29 are most at risk of HIV infection, with an HIV prevalence in this age group of 33.3%. Men between the ages of 30 and 39 are most at risk with a prevalence of 23.3% (HSRC[3], 2005).

Of particular concern is that there are still a large number of new HIV infections. The annual antenatal surveys show a steady increase in HIV prevalence since 1990, to over 29% of pregnant women in the 2004 survey (released 2005). Our current efforts to improve the prevention of HIV are not working sufficiently. The Actuarial Society of South Africa's ASSA2003 model estimates that there are still over 400,000 new infections a year, i.e. more than 1,000 people are infected per day on average. While some progress is being made reducing new infections, the available evidence suggests that current interventions are insufficient.

With regard to treatment, ASSA2003 estimates that over 500,000 people now have AIDS and require highly active antiretroviral therapy (HAART), but are not currently on HAART. Without such treatment, nearly all of those with AIDS will

3 South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2005.

likely die in the next two to three years. At present approximately 110,000 public sector and 80,000 private sector patients are receiving treatment.[4]

The HIV epidemic has resulted in a crisis of mortality. Life-expectancy in South Africa has dropped from over 60 in 1996 to just over 50 in 2005. As stated above, according to ASSA over 300,000 people died of AIDS last year. A recently released Statistics South Africa report showed a 57% increase in mortality between 1997 and 2002. Only a small percentage of this can be accounted for with improved death registration and population growth; the remainder is likely due to the HIV epidemic.[5]

On top of the challenge of the HIV epidemic, democratic South Africa inherited a health system characterised by inequality and inappropriate use of resources. A consequence of Apartheid and colonialism is that private health facilities offer first-class medical care at an exorbitant cost to a small, predominantly white, part of the population, while black people mainly use public health facilities, of which there are too few. Public health facilities are understaffed, require many patients to embark on long and expensive travelling routes to get assistance and are frequently understocked with essential medicines and equipment.

At a time when HIV was predominantly affecting gay men and migrant labourers, the Apartheid Government made little effort to promote HIV prevention, although intervention at that stage would have been critical. For example, in 1990, Thailand's HIV epidemic was comparable in size to South Africa's. In 2005, Thailand has a small epidemic, while South Africa has one of the world's largest. Part of Thailand's successful response has been credited to action taken in the early 1990s. Responding to the HIV epidemic as it escalated during the period of transition from Apartheid to democracy was an immensely difficult task from the outset, but made all the more difficult by what at the time appeared to be the more pressing challenges of the transition, including building South Africa's democratic structures and resolving violence in much of the country.

Much further research has been done demonstrating the effect of HIV on the increasing number of orphans, its effect on households and its contribution to poverty. The HIV epidemic challenges the socio-economic development of our country. A successful response to it requires leadership and good governance. It is therefore appropriate that the African Union Peer Review Mechanism is considering the HIV epidemic in its deliberations. At issue in these deliberations should be the state’s response to the epidemic and whether it has discharged its international and domestic human rights obligations in so doing.

As we show in this submission, while a number of important interventions have been implemented to respond to the HIV crisis, there has been a lack of leadership from the highest political level, especially from President Mbeki and the Minister of Health. This lack of leadership, which has been epitomised by expressions of support for pseudo-scientific views on the HIV epidemic, has

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4 Briefing by convener of the Joint Civil Society Monitoring Forum for TAC NEC January 2006.

5 Bradshaw D., Laubscher R., Dorrington R. E., et al. (2004) Unabated rise in number of adult deaths in South Africa. South African Medical Journal. 94(4): 278-279.

resulted in a lack of co-ordination at national level of worthy interventions. Consequently, time and resources have been wasted, with the effect that many people have become unnecessarily infected with HIV and many have died avoidable deaths due to AIDS.

This submission will review the response of the South Africa government to the HIV/AIDS epidemic. This will be begun by establishing the legal responsibility upon the government, to be followed by a summary of the areas where government has fulfilled its obligations and those where it has not. The submission will then proceed to examine the governance practised by the state with regard to the HIV epidemic. It will be shown that successes achieved have been largely despite government, not because of it. Furthermore, the trend of undermining key institutions of democracy will be demonstrated. Lastly the report will examine the role of parliament and argue for a stronger role for the Parliamentary Portfolio Committee on Health. What follows, read with the appendix, which further charts the government's unsatisfactory response, makes a compelling case for the recommendations made earlier in this submission.

Response to the HIV epidemic

Government has a duty to respond appropriately to the HIV epidemic. This assertion is based on numerous treaties and legal documents. Article 25 of the UN Declaration of Human Rights states:

> *Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services.*

The African Charter of Human and Peoples' Rights states as follows in Article 16:

> *(1) Every individual shall have the right to enjoy the best attainable state of physical and mental health.*
>
> *(2) States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.*

The South African Constitution at Section 27 states:

> *(1) Everyone has the right to have access to- ... health care services, including reproductive health care.*
>
> *(2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.*

The Rome Statute of the International Criminal Court includes in its definition of extermination –which it describes as a crime against humanity–

> *"the intentional infliction of conditions of life, inter alia the deprivation of access to food and **medicine**, calculated to bring about the destruction of part of a population". [our emphasis]*

The duty of the state is therefore substantial. In alleviating the HIV epidemic, the state must take cognisance of effective prevention interventions, as well as providing life-saving medicines to the sick. When the government responds, as is its duty, it must do so on the basis of the best available scientific evidence. Clearly however, the state can only be expected to do what is possible. State action is limited by the resources available to it. However, South Africa is a middle-income country and various analyses have demonstrated that prevention and treatment interventions for HIV are affordable[6].

The South African Government has implemented the following key interventions to alleviate the HIV epidemic:

- There is a legal framework in place to protect people with HIV from unfair discrimination.
- Government has developed various plans to deal with HIV including a strategic framework (which expired at the end of 2005). This strategic framework was designed to bring together the various components of the government's approach to combating HIV/AIDS, namely: (1) prevention; (2) treatment, care, and support; (3) research, monitoring and surveillance; and (4) legal and human rights. Government also introduced the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa published on 19 November 2003 (Operational Plan).
- Free condom distribution is extensive. It has increased from just under 270 million male condoms in 2001 to about 350 million male condoms in 2004 (HSRC, 2005).
- Voluntary counselling and testing for HIV is available at thousands of health facilities across the country.
- A public information programme on HIV is run through the government sponsored Khomanani initiative. Government also contributes substantially to the Soul City and loveLife campaigns.
- Syndromic management of sexually transmitted infections, a key intervention for reducing transmission of HIV, is government policy.
- A mother-to-child transmission prevention programme has been implemented in over 1,500 clinics.
- Post-exposure prophylaxis has been made available at some clinics across the country.

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6 For example, see Geffen, N., Nattrass, N. & Raubenheimer, C. (2003) The cost of HIV/AIDS prevention and treatment interventions. Centre for Social Science, Research Working Paper No. 29. Centre for Social Science Research, University of Cape Town. Available at: www.uct.ac.za/depts/cssr

- In principle, there is universal access to treatment for all opportunistic infections associated with HIV.
- According to government, HAART was available at 192 facilities and 78,000 people has initiated treatment as of end of August 2005 (Ministry of Health Statement, 25 October 2005). President Mbeki indicated that about 100,000 receive HAART in his 2006 state of the nation address. This estimate concurs with one made by the Joint Civil Society Monitoring Forum (JCSMF) for the end of December 2005. The JCSMF estimates that approximately a further 90,000 people receive treatment through private initiatives, meaning that nearly 200,000 people in South Africa were receiving HAART by the beginning of January 2006.[7]
- South Africa invests a large amount of money in alleviating the HIV epidemic. The Treasury's health HIV/AIDS budget is R1.5 billion for 2005/6. Treasury estimates a 24% increase for 2006/7. The HIV/AIDS conditional grant grew 38% in 2005/6 and is predicted to grow a further 31% in 2006/7.[8]
- Government has in place an extensive social assistance system that contributes to poverty alleviation. This system includes a disability grant for poor people with AIDS who are unable to work. The social grant system helps people with HIV purchase food and it might have the effect of creating a greater degree of financial independence for some women, thereby giving them greater power in their sexual relations.

The above demonstrates that substantial work is being done to alleviate the HIV epidemic. However, as we now show many of these interventions are beset with problems. In the governance section we will show evidence that poor governance characterised by lack of leadership from President Mbeki and Minister Tshabalala-Msimang has been the key obstacle to the response to the HIV epidemic.

The response to the HIV epidemic has at least the following serious shortcomings:

- Government's public messaging on HIV is often characterised by confusion. The Minister of Health, President and other ruling party officials have given credence to the pseudo-scientific views that HIV does not cause AIDS and that antiretroviral treatment is toxic to the point that its risks outweigh its benefits. The President has also sympathised with the view that people with AIDS are not dying in large numbers, despite the plethora of evidence to the contrary[9]. We explain this in further detail in the governance section. Khomanani advertisements are infrequently run on television and radio. At

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7 Briefing by convener of the Joint Civil Society Monitoring Forum for TAC NEC January 2006. The JCSMF estimated 110,000 people receiving treatment in the public sector as of the beginning of January 2006.

8 National Treasury Estimates of National Expenditure 2005, pages 346-347.

9 For a collection of the President's confusing statements on HIV/AIDS, see http://www.tac.org.za/Documents/Other/Mbeki-on-HIVAids-Updated.doc

times they have addressed key issues such as the rollout of HAART and safer sex. Often they have been insipid, in that the need to combat AIDS has been referred to in a generalised and directionless manner.

- The legal framework still has a number of gaps which require attention, including further regulation of private social security and the amendment of the Equality Act in line with the Equality Review Committee's recommendations on HIV/AIDS. Also, the National Health Act provides no legal or policy framework for genuine health sector transformation. Another leg of the legal framework is the Patent Act which provides patent protection (at the expense of access) in excess of what South Africa is obliged to provide under international trade law.

- Voluntary counselling and testing is unstandardised across the country and is not sufficiently widely available, especially not in health-care settings. It is consequently poor in many, perhaps most of those clinics where it is offered. This is a lost opportunity for HIV prevention and patient education, as this intervention has been shown in an East African study to be effective at changing sexual behaviour if it is accompanied by a safer sex component.[10] Furthermore, the promotion of voluntary counselling and testing is insufficient and the link between testing and accessing treatment is not made clear enough.

- Condom distribution is unaccompanied by sufficient targeted programmes for encouraging safer sex. For example, there is inconsistency in condom and safer sex promotion in schools, as well as in voluntary counselling and testing for HIV. Female condoms are also distributed in insufficient numbers and government has failed to put pressure on the patent-holder to lower its price or allow generic manufacturers of the femidom.

- The public health system is in crisis. It endures a severe shortage of resources. There are too few facilities in many areas. For example, Khayelitsha has a population exceeding 500,000 but it is only served by three clinics, whereas to meet the UN's Inter-Agency Standing Committee recommended population to clinic ratio, it requires at least ten.[11] Government has no plan in place to address the human resources and clinic shortage. Clinics are also burdened with equipment and medicine shortages.

  There is a severe human resources crisis in the public health system, with drastic shortages of nurses, doctors, pharmacists, social workers, counsellors, nutritionists, administrators, managers, porters and cleaners. This is exacerbated by the increased burden of patients due to the HIV epidemic and high HIV prevalence among health workers. The Operational

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10 Voluntary HIV-1 Counselling and Testing Efficacy Study Group (VCTESG). (2000) Efficacy of voluntary HIV-1 counselling and testing in individuals and couples in Kenya, Tanzania and Trinidad: a randomised trial. The Lancet. Vol. 356, 103 – 112.

11 Sphere Project: http://www.sphereproject.org/handbook/html/7_ch5.htm. Last accessed 13/2/2006. This is a project of the International Red Cross and its standards are endorsed by the UN's Inter-Agency Standing Committee.

Plan committed to an additional 22,000 health-care workers in the public health system by 2008 just to deal with the HIV epidemic. But there is no plan in place to make this happen and consequently no evidence that the human resources crisis is improving. In recent months the Department of Health has released two important documents. One is the *Strategic Framework for the Human Resources for Health Plan*. The other is the new Nursing Bill. Both documents have serious problems and fail to address the human resource crisis sufficiently.

- While the mother-to-child transmission prevention programme is widespread, the sub-optimal single-dose nevirapine regimen is used in all but one province. Consequently transmission rates are unnecessarily high and women on the programme are put at risk of becoming resistant to nevirapine which limits their options when they initiate HAART. The single-dose nevirapine regimen is much better than no intervention, but a simple improvement to it, such as initiating short-course AZT in conjunction with it as has been done in the Western Cape, would yield much better results. The mother-to-child transmission prevention programme was implemented years later than it should have been and only after successful court action from the TAC and others.

- The availability of post-exposure prophylaxis at clinics is patchy and poorly advertised. There are also other barriers to access, like the requirement of a rape charge.

- Key opportunistic infection medicines continue to be unavailable in many clinics. Government has a policy to make fluconazole for treating cryptococcal meningitis and systemic thrush available in many clinics, but most clinics still do not receive this medicine. The above policy was itself only brought into being because of pressure from the TAC, including a defiance campaign. Amphotericin B, a critical medicine for the initial treatment of cryptococcal meningitis, is available at very few facilities even though TAC together with the AIDS Law Project recently pressured the manufacturer into making it available to government at a substantially reduced price. Acyclovir for treating Herpes is also only available in very few clinics. The TB treatment programme is also beset with problems reflected in low cure-rates.

- The HAART rollout is far behind the targets of the Operational Plan. According to this plan there were supposed to be 188,000 people on treatment by the end of the 2004/5 financial year (March 2005) and 381,000 people on treatment by the end of this financial year (March 2006). Some provinces, for example Mpumalanga, are proceeding far too slowly. Furthermore, the monitoring and evaluation of the programme is wholly inadequate because of a lack of national leadership of the programme. The government has spoken about the need for pharmacovigilance and about the need to monitor and evaluate the Operational Plan, but none of these steps have been implemented, which leads us to question government’s commitment to evaluate the programme’s implementation with a view to improving it. Consequently the statistic of 100,000 people on HAART must be accepted with caution. Information on patient outcomes comes mainly

from NGOs assisting with the implementation of subsections of the programme, as well as from the National Health Laboratory Service. Despite abundant information there is apparently no co-ordinated government effort to determine the successes and challenges of the programme. The HAART rollout is characterised by long waiting lists and most patients initiating therapy with low CD4 counts. Finally, many of the patients on HAART in the public sector are being treated by NGOs working in partnership with government (e.g. MSF and ARK). While this is acceptable for the initiation of the programme, we are concerned that not enough is being done by government to ensure that these NGOs can exit from the HAART rollout.

The HAART programme was implemented years later than it should have been and only after extensive campaigning from the Treatment Action Campaign and others including a civil disobedience campaign and numerous threats of litigation, one of which was averted from going to court at the last hour when government agreed to allow procurement of antiretrovirals on an interim basis while the tender for these medicines was still being finalised.[12]

- Despite much talk by the Minister of Health on the importance of nutrition in alleviating HIV, a report by the Joint Civil Society Monitoring Forum that examined the implementation of the nutritional aspects of the Operational Plan found that nutritional initiatives were inadequate, inconsistent and mostly poorly implemented.[13] No government fact sheet on nutrition aimed at laypeople has been released (this has however been done by TAC and Soul City). Vitamin supplements are offered to people with HIV in many clinics but inconsistently. A recent study in Tanzania found that a particular combination of vitamins slightly, but significantly, reduces progression to AIDS[14], but there appears to be no proper protocol in place in the public health sector as to which vitamins should be offered and it is not clear that the same regimen tested in Tanzania is offered in all clinics.
- The social grant system has some inadequacies. For example, low-income people with low CD4 counts receiving this disability grant lose that grant once they have initiated antiretroviral treatment and recovered sufficiently. They are left with the unacceptable choice between giving up antiretroviral treatment so that they become eligible for the grant again or reducing their access to food security. No mechanism has been put in place to address this problem.

In summary, there is much to be done before South Africa's response to the HIV epidemic can be considered successful. Tragically, hundreds of thousands of people still face death in the next year because they will not be able to access HAART.

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12 TAC Electronic Newsletter March 25 2004.

13 JCSMF Report on the 5th JCSMF Meeting held on 29 Aug 2005, Khayelitsha, Western Cape. Accessed at: http://www.hst.org/uploads/files/jcsmf.290805.pdf.

14 N Engl J Med. 2004 Jul 1;351(1):23-32.

Governance and HIV

It is a factor of the strength of South Africa's democracy that despite the President and Minister of Health's lack of leadership on HIV and their perceived sympathy with pseudo-scientific views --i.e. that HIV is not the cause of AIDS, antiretrovirals are unsafe and ineffective against AIDS and there has not been a massive increase in the number of people dying of AIDS in South Africa--, the country has proceeded with a response to the epidemic that includes the rollout of HAART and condom promotion, interventions that are inconsistent with the denialist position.

This has predominantly been a consequence of civil society action, clinicians, researchers, many civil servants and a few politicians dedicated to responding adequately to the epidemic, media criticism of the government's response to HIV and the strength of the Constitution as well as its enforcement by the courts. It is also through the freedom of expression and assembly guarantees in the Constitution's Bill of Rights that civil society and media have been able to criticise government's failure to act appropriately on HIV.

Good governance requires that public policy on health be based on the best available current science. Unless there is compelling evidence to the contrary, public policy and the statements of public officials should not contradict scientific consensus on health matters, especially where such consensus is unanimous amongst all credible scientific institutions. Tragically, this principle has not been followed in South Africa.

The President, Minister of Health and other government officials have on numerous occasions conducted themselves unfittingly in the response to the HIV epidemic, abused their power and obstructed the response to the epidemic. They continue to do so. The successful aspects of the response to the HIV epidemic have occurred despite the President, Minister of Health and these officials, not because of them. Their actions, or the actions of other officials acting under their instruction or perceived approval, have on frequent occasions been examples of anti-democratic behaviour and poor governance. We describe some of these actions in the appendix to this submission. This list is by no means comprehensive:

The manner in which President Thabo Mbeki has encouraged and defended AIDS denialism has been widely examined.[15] Government and ANC spokespersons have been at pains to insist that President Mbeki has not expressly or publicly “ever denied a link between HIV and AIDS”.[16] He

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15 See M Heywood, Preventing Mother to Child HIV Transmission in South Africa: Background, Strategies and Outcomes of the TAC case against the Minister of Health, SA Journal on Human Rights, Vol 19: Part 2, 2003; M Mbali, ‘Mbeki’s Denialism and the Ghosts of Apartheid and Colonialism for Post-apartheid policy making’; M Schoofs, ‘Flirting with Pseudo-Science’ Village Voice, March 15-21, 2000.

16 Government and ANC spokespersons have been at pains to stress this point. See, ‘Building a Monument to Intolerance’, Release from Mr Parks Mankahlana, Head of Communications, President Mbeki’s Office, 23 March 2000; ‘Response to Enquiries and Comments on HIV/AIDS’,

questioned in Parliament how a virus could cause a syndrome. He has also never publicly affirmed that HIV does cause AIDS. Instead he has left a paper trail of his questions about HIV and hints about his sympathies with the denialists, the impact of which can be traced through what was not done by his government as well as what was questioned and resisted.[17]

The tragic consequences of denialism have been the delayed and/or muted implementation of HIV programmes and public confusion. This has resulted in numerous avoidable deaths.

This has been epitomised by the dysfunctionality of the South African National AIDS Council (SANAC). SANAC was established in 2000 to be the highest national advisory body on HIV/AIDS, a role it is not seen to fulfil. Its conduct has been characterised by few meetings, missed meetings, a lack of accountability and poor leadership. When meetings have happened the agendas have been drafted late and without consultation. SANAC has received two qualified audits from the Auditor-General.

Furthermore, SANAC is the official South African co-ordinating mechanism for grant proposals to the Global Fund to Fight AIDS, TB and Malaria (Global Fund). It's lack of co-ordination and tardiness have resulted in a number of grant opportunities being lost or grants of poor quality being sent to the Global Fund.

The Minister of Health and previous SANAC chairperson, former Deputy President Jacob Zuma, failed to ensure that most of the R30 million used to establish SANAC in 2002 was spent. As of February 2005 only R520,000 of this money had been used. A large portion of this has been wasted on unoccupied offices for the SANAC secretariat, something that has drawn criticism from the Auditor-General.

A concerning aspect of the poor governance of the HIV epidemic has been long-term institutional damage, particularly to the Medicines Control Council (MCC) and the Medical Research Council (MRC). It is essential that these institutions operate independently, i.e. without political interference. Their independence has been affected by changes to the Medicines Act which empowered the Minister of Health with undue influence. The threats to the independence of these essential institutions are a symptom of the poor governance of the HIV epidemic.

In 1998, the MCC refused to allow further testing of a toxic substance, Virodene, purported to be a treatment for HIV. President Mbeki responded by criticising the MCC (see appendix). The rift between government and the MCC over Virodene resulted in the resignation of the MCC chairperson. Since the Virodene incident, the Minister of Health has been given the power to appoint a Registrar of Medicines on the MCC. Consequently the MCC has become increasingly less independent.

Statement Issued on Behalf of the Government 14 September 2000.

17 Price of Denial, Mark Heywood, available from www.tac.org.za.

For example, during the mother-to-child transmission prevention court case between TAC and government, the MCC equivocated on emphasising the safety and efficacy of nevirapine on several occasions. Statements questioning the safety and efficacy of nevirapine were released by the MCC which co-incidentally occurred just before critical court dates. In a radio interview on SAFM, the MCC chairperson, Professor Peter Eagles, implied that research on nevirapine had not been tested in an African setting, ignoring both the HIVNET 012 (UGANDA) and SAINT (South Africa) trials of nevirapine for mother-to-child transmission prevention. Furthermore, in contrast to its vigilance during the Virodene affair, the MCC has failed to take action –and failed to ask the Department of Health to take action, as it is legally entitled to do– against the pharmaceutical proprietor Matthias Rath who makes pseudo-scientific claims about HIV treatment that have found resonance with the Minister of Health. This is despite receiving evidence from TAC and other organisations and individuals of Rath's activities.

Incidents relating to the reduced independence of the MRC are described in the appendix.

TAC's direct experiences with the Commission on Gender Equality and the Independent Complaints Directorate (ICD), where we have encountered a lack of boldness to act on governance issues, also increase our concern that the independence of key institutions is under threat. TAC is still awaiting reports on complaints lodged with the ICD concerning police actions during two TAC demonstrations, one having taken place in 2003 and the other in July 2005. TAC has attempted to get the Gender Commission to take a more active stance on HIV, but the Commission has failed to produce anything substantive.

Role of Parliament

TAC monitors, observes and participates in parliamentary hearings relevant to health and HIV. Most of our experience in this regard has been with the Parliamentary Portfolio Committee on Health.

This committee has held numerous important hearings on topics in which TAC has participated. Some examples of this are drug pricing, the registration of nevirapine for mother-to-child transmission prevention and the collapse of the NEDLAC agreement on HIV. We have found the committee an important forum in which to raise concerns and ideas. On numerous occasions, together with the AIDS Law Project, we have presented submissions on health legislation to this committee. Its work is important.

However, our main concern with the Parliamentary Portfolio Committee on Health is that it lacks powers for, or does not perform, sufficient oversight of the Minister of Health and the Department of Health. While much that the Department and Minister do (or do not do) is discussed in this forum, there appears to be little done when the Department or Minister's performance is questionable. The committee is largely failing to hold the executive to account.

The Matthias Rath episode epitomises this. Rath is a pharmaceutical proprietor who has been making false claims about his drugs, distributing unregistered medicines and conducting an unauthorised clinical trial experimenting on

people. His activities are dangerous and threaten public health. The TAC has analysed five deaths on this trial and we have been informed of several more[18]. Furthermore, Rath's advertising campaign has caused confusion on a large scale because he has made use of mass media and distributed tens of thousands of pamphlets making false claims. The Minister of Health has given support to Rath, or at a minimum failed to condemn and stop him. Complaints have been lodged against Rath with the law enforcement unit of the Department of Health, yet no action has been taken. This was an opportunity for the Parliamentary Portfolio Committee to act by summoning the Minister of Health to a committee hearing and questioning her on the Rath issue. Yet, the committee has taken no action on this matter.

Conclusions

Finally, despite the numerous concerns we have raised here, we are confident that significant progress will be made in the alleviation of the HIV epidemic and the improvement of public health-care generally. We are also confident that the time of perceived support by the South African government for pseudo-science will soon end. We endeavour to work with the Ministry of Health, Department of Health and the Parliamentary Portfolio Committee on Health to respond adequately to the HIV epidemic.

[END OF SUBMISSION – APPENDIX FOLLOWS]

18 It is our view that the evidence shows that Rath shares partial responsibility for three of these deaths and conveniently ignores the other deaths in his marketing materials which exaggerate the efficacy of micronutrients and multivitamins.

Appendix: Partial Record of government actions demonstrating poor governance and a lack of leadership on HIV

- It is worth noting just a few of the President's statements that have undermined government response to the HIV epidemic[19]:

  “To quote Carter Woodson, these [black people] have studied in...medical schools where they are likewise convinced of their inferiority by being reminded of their role as germ carriers; schools where they learn a history that pictures black people as human beings of the lower order, unable to subject passion to reason.

  And thus does it happen that others who consider themselves to be our leaders take to the streets carrying their placards, to demand that because we are germ carriers, and human beings of a lower order that cannot subject its passions to reason, we must perforce adopt strange opinions, to save a depraved and diseased people from perishing from self-inflicted disease.

  *Convinced that we are but natural-born, promiscuous carriers of germs, unique in the world, ["others who consider themselves to be our leaders"] they proclaim that our continent is doomed to an inevitable mortal end because of our unconquerable devotion to the sin of lust.”(*Address at the Inaugural ZK Matthews Memorial Lecture, University of Fort Hare, 12 October 2001)

  "*I have said to the Minister of Health, have we looked at the radically revised guidelines the US government issued at the beginning of this year about treatment with antiretroviral drugs where they have said that these drugs are becoming as dangerous to health as the thing they are supposed to treat.*" (quoted in Business Day, 25 October 2001 – the guidelines Mbeki was referring to said no such thing)

  “There is no need for me to emphasise the point that, necessarily, the government has to respond to the objective reality of the health profile of our country and not what we or other people wish it to be or mistakenly assume it to be. It may be, of course, that the issue is more complex than I am stating it.

  Needless to say, these figures will provoke a howl of displeasure and a concerted propaganda campaign among those who have convinced themselves that HIV/AIDS is the single biggest cause of death in our country.

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19 For a more comprehensive list of President Mbeki's statements on AIDS sympathetic to denialism or that revise the history of this saga, see http://www.tac.org.za/Documents/Other/Mbeki-on-HIVAids-Updated.doc

These are the people whose prejudices led them to discover the false reality, among other things, that we are running out of space in our cemeteries as a result of unprecedented deaths caused by HIV/AIDS. In this context, I must also make a point that we have to act without delay on the proposal made by the Presidential AIDS Panel that, among other things, an investigation be made of the HIV and AIDS statistics that are regularly peddled as a true representation of what is happening in our country."
(Letter to Minister of Health dated 6 August 2001)

In an interview on ETV in April 2001, President Mbeki said he would not take a public HIV test. His reasoning was *"I go and do a test - I am confirming a particular paradigm."*

- In 1997 and 1998, Government gave undue prominence to an unproven and dangerous treatment for HIV called Virodene, which had been tested without authorisation on human subjects. The MCC conducted an investigation of Virodene and refused to grant permission for further research on people. In response, Mbeki defended the research in the ANC's newspaper Mayibuye, and accused the MCC of using its 'powers to decide who shall live or die' to deny 'dying AIDS sufferers the possibility of 'mercy treatment' to which they are morally entitled.'[20] This shows the governments willingness to push for an unproven drug (similar to the Minister's push for unproven traditional medicines) whilst exercising extreme caution in respect of approved drugs.
- In 2000, the President set up an AIDS advisory panel which included numerous AIDS denialists, almost in equal proportion to scientists proposing the indisputable conventional science. Instead of determining an appropriate response to the HIV epidemic, this panel diverted attention to the already answered questions as to whether HIV causes AIDS and whether the benefits of antiretrovirals outweigh their risks. Much time and money was wasted. Much confusion was generated.
- The Minister of Health has acted and made statements that can only be interpreted as sympathetic to pseudo-scientific responses to the HIV epidemic. Here are a few examples:

  The Minister frequently points out the side-effects and toxicity of antiretroviral treatment. Not once has she endorsed them, promoted them, pointed out their benefits, or told the public to consider their use.

  The Minister has endorsed certain foodstuffs as treatments for AIDS including garlic, lemon juice, olive oil and the African potato. While

20 T Mbeki, 'ANC has no financial stake in Virodene', *Mayibuye*, March 1998. Subsequent research by investigative journalists has suggested that the ANC's interest in Virodene was not purely publicly minded. See *Mail and Guardian*, July 5 2002 "The ANC's Virodene backers": "The ANC secretly arranged millions of Rands in funding for Virodene."

garlic and olive oil are undoubtedly healthy foods to eat, there is no scientific evidence that they treat HIV or AIDS. A trial on extract of African Potato (hypoxis) for the treatment of HIV had to be terminated prematurely because of its side-effects. She has never admitted this fact publicly.

The Minister frequently promotes traditional medicines as treatments for AIDS. Not once has she pointed out that none are registered with the Medicines Control Council for this purpose, nor has she ever noted that some traditional medicines are associated with side-effects. There is therefore an inconsistency between the Minister of Health's public statements on medicines registered for the treatment of HIV (i.e. antiretrovirals) and those not registered for such treatment (garlic, lemon juice, olive oil, African potato and traditional medicines). The TAC's view is that traditional medicines might have a role in the treatment of HIV, but government's role is to ensure that investment in the research of these medicines takes place. It cannot promote medicines that have not yet been shown scientifically to be effective.

In a radio interview conducted on Radio 702 in September 2000, the Minister was asked directly if she believes that HIV causes AIDS. She refused to answer despite being asked the question repeatedly. An argument resulted between her and the radio presenter, John Robbie. To our knowledge, the Minister has never unequivocally stated in public that HIV causes AIDS.

The Minister has at times been advised by AIDS denialists including Roberto Giraldo.

The Minister had a private meeting on 16 April 2005 with the pharmaceutical proprietor, Matthias Rath, a person with rulings and warnings against him from courts and various authorities in multiple countries for making false claims about his products in the treatment of diabetes, heart disease, cancer and HIV. Rath has been running adverts in South Africa making false claims about the treatment of HIV. The minister has been quoted in the media offering her support for him. In a public meeting on 16 April 2005, where Rath sat in the audience, she refused to condemn him despite being asked to do so by numerous attendants to the meeting. Rath has in public statements claimed her support. She has not denied this. In a written statement to Parliament she said she would refuse to distance herself from Rath until it was shown that the "*supplements that he is prescribing are poisonous for people infected with HIV.*"[21] This approach undermines science; it is safety that must be proven before promoting medicines to people, not the other way around. Her statement also ignores Rath's attempts to undermine the antiretroviral rollout.

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21 See http://www.tac.org.za/Documents/HealthMinisterCase.html for more details. See full court papers TAC and SAMA v. Rath and Others (including Minister of Health), Cape High Court.

AIDS denialists David Rasnick and Sam Mhlongo who collaborate with Rath were invited by the Minister to present (in September 2005) to the National Health Council on an illegal clinical trial they conducted in Khayelitsha.

The Minister has appeared in a supportive role in a propaganda video produced by Tine van der Maas, who promotes a concoction of garlic and African potato as an exclusive treatment for AIDS, diabetes and other diseases. The Minister has promoted this video at various forums.

At a media briefing at an AIDS Conference in Durban in June, the Minister was widely quoted as saying "I know I get attacked if I say it's nutrition or micro-nutrients or antiretrovirals and people want me to say, and, and, and. I think we need to give South Africans options ... "[22]

In a written statement to Parliament in September the Minister stated:
"Firstly, I have never said that traditional medicines and vitamins should be offered as alternatives, which means instead of ART. What I have emphasized is that our people must be given a choice."
She further states:
"Certain traditional medicines may help to treat numerous symptoms of opportunistic infections that are part of AIDS. They represent alternatives to formal general medicine and for many people will be the only options they have."
But in terms of good governance the Minister's obligation is to provide public information based on the best available scientific evidence and current policy. Individuals in society then make choices as to whether or not to follow these recommendations. The Minister should not be providing choices between an approach that the scientific consensus recommends and one that has no scientific basis at all.

- TAC and other organisations and individuals have lodged complaints with the Medicines Control Council, Department of Health and police about the illegal activities of Matthias Rath including his false claims about his medicines, unauthorised clinical trial in Khayelitsha, distribution of unregistered medicines and practising as a medical doctor without being registered with the HPCSA. No action has been taken, despite these complaints being lodged as far back as February 2005, the provision to the relevant authorities of evidence and the subsequent reports of deaths on Rath's trials. Consequently TAC together with the South African Medical Association has proceeded with litigation to compel the Minister of Health and Medicines Control Council to act against Rath.

- An AIDS denialist document titled *"Castro Hlongwane, Caravans, Cats, Geese, Foot & Mouth and Statistics"* which contains a pseudo-scientific condemnation of antiretroviral treatment as well as denial of the extent of the epidemic in South Africa was widely circulated to ANC branches apparently with the apparent approval of the President and the late ANC

22 http://www.news24.com/News24/South_Africa/Aids_Focus/0,,2-7-659_1717650,00.html

Youth League Chair, Peter Mokaba. Mokaba, before his death, never denied allegations that he helped write this document.

- In December 2004, the ruling party's on-line newsletter ran an attack on nevirapine claiming that it was unsafe. It attacked the TAC in particular for its stance on nevirapine and it attacked the HIVNET 012 trial that took place in Uganda. The missive was based on an Associated Press report that was inaccurate. The HIVNET 012 trial, before and after the Associated Press report, has been found in audits and independent investigations to be scientifically sound, yet no correction of the above on-line statement has been published nor has there been an acknowledgement of the findings that the HIVNET 012 trial results were accurate. The ruling party has never responded to TAC's request for a right to reply to their inaccurate report.
- On several occasions TAC has had to litigate to change government policy:
- TAC and others took government to court to compel it to implement a country-wide mother-to-child transmission prevention programme in 2001. The Pretoria High Court ruled in TAC's favour. This was appealed by government. TAC then received a ruling for interim relief, also appealed by government. The Constitutional Court finalised the matter by ruling in favour of TAC.
- Subsequent to this, Mpumalanga Province continued to fail to rollout mother-to-child transmission prevention. Only following a threat of legal action from TAC for contempt of court did the rollout proceed.
- Following the publication of the Operational Plan (under instruction from Cabinet) the antiretroviral rollout stalled in all provinces except the Western Cape. This was due to the Minister of Health refusing to allow provinces to purchase an interim supply of antiretrovirals while the tender for these medicines was being finalised. TAC threatened to take legal action. Such action was averted at the final hour when government agreed to allow interim procurement, but the refusal to allow interim procurement resulted in the rollout of HAART being delayed by several months.
- In 2004, TAC litigated against government under South Africa's Access to Information Act for failing to make the timetable for the rollout of the Operational Plan publicly available. The Pretoria High Court ruled in TAC's favour. Furthermore, due to the delinquent behaviour of the Minister and her department in failing to respond to our request for the timetable and inform us that only a draft had been done (despite eleven different opportunities to do so) TAC had no choice but to proceed to obtain a cost order against the minister in court.
- Government pulled out of signing an agreement on responding to the HIV epidemic at NEDLAC after verbal agreement had been reached on the contents of the document towards the end of 2002. From the perspective of anyone who recognises that HIV causes AIDS, it is to this day unclear why this withdrawal took place as it resulted in a further delay in the rollout of HAART, as well as other useful interventions.

- Government spending on HIV has been beset with problems and mismanagement. We note the following:

  There was misappropriation of funds in Mpumalanga in 2003 by the Provincial Health Department under MEC Manana, including diversion of HIV funds to soccer events. This mismanagement of funds was confirmed by subsequent dealings between the Auditor-General and the Mpumalanga Health Department. Ms. Manana is now a Member of Parliament and a member of the Health Committee.

  Following a complaint from TAC, the Auditor-General issued a qualified audit of the Department of Health in 2004, owing to a range of issues, and particularly because NGOs had failed to account for their expenditure in terms of the Public Finance Management Act. Specifically cited was the National Association of People with AIDS (NAPWA), about whom TAC had complained. NAPWA had been operating, funded in large part by government, for years amidst reports of corruption. The organisation appeared to have no substantive programme other than to contradict the actions of TAC and its allies. The Department of Health's papers suggest that NAPWA has been used to undermine TAC, and seem to implicity recognise the need to fund NAPWA as a counter to TAC. This is encapsulated in the following allegation made after the Auditor-General's findings, by Lucky Mazibuko in Sowetan newspaper "*Napwa became a perfect and convenient restorer of credibility in the Government's continued legitimisation of the Department of Health's outright refusal to provide anti-retroviral treatment to millions of people living with HIV and Aids. ... Napwa was strategically ... manipulated [by the Department of Health] into becoming an unofficial spin doctoring cover ...* "[23].

  We concur with Mazibuko's opinion. It is supported by the fact that NAPWA has formed an alliance with Matthias Rath in his dispute with TAC, including submitting a letter of support for Rath in a court case between us earlier this year and admitting to receiving funds from Rath. In our view NAPWA has been used by the Minister of Health as a bulwark against TAC.

- Government has a track record of ignoring invitations to TAC events and TAC correspondence. This is unacceptable, especially since TAC is recognised worldwide as the foremost HIV activist organisation in the country. Although TAC has disputes with government, this is insufficient reason to boycott TAC events and to ignore requests for meetings and information. Yet, the Minister of Health frequently meets with, and offers support to, discredited individuals such as Matthias Rath, David Rasnick, Sam Mhlongo and Roberto Girraldo as described above. For example, no government representative attended the recent TAC National Congress, despite invitations being sent to all MEC's for Health, the Minister of Health and many others.

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23 Lucky Mazibuko, The Sowetan, 12 October 2004

- On two occasions, TAC demonstrators have been assaulted by police. The first incident took place in Durban in March 2003. The other took place in Queenstown in July 2005. In both cases, TAC demonstrators were in violation of the law, but the protests were peaceful acts of civil disobedience and the police should have arrested demonstrators, not used violent force. TAC acted in violation of the law only after all other courses of action had proven unsuccessful – when all attempts at dialogue and engagement had been spurned. Police action in the Queenstown case has been condemned by UNAIDS and numerous other organisations. A complaint was lodged by TAC with the Independent Complaints Directorate, but to date they have not published the results of their investigation.

- On several occasions government has held back reports or attempted to stop the publication of reports on the HIV epidemic. For example:

  TAC obtained from a confidential source a government report in 2003 which had found that a HAART programme could save the lives of 1.7 million people by 2010. We made this report available to the media. This report should have been made available by government as soon as it was ready, yet government chose not to make it public.

  A Medical Research Council report on mortality due to HIV was released to the media in 2002. Instead of the Ministry of Health responding to the serious concerns raised in the report about the effect of HIV on adult mortality, the Medical Research Council board launched an investigation to determine who leaked the report.

- The previous president of the MRC, Professor Malegapura Makgoba has a distinguished research record, particularly in HIV. His successor and the current president, Professor Anthony Mbewu is recognised more for his administrative achievements. Unfortunately, he has made a number of statements on HIV which are inaccurate and show inclination towards the pseudo-scientific AIDS denialist position. For example he stated:

  “The nation is in poor health, with just as many if not more deaths from heart disease and strokes than AIDS ... AIDS is a major problem, but heart disease and strokes are much bigger.”[24]

  This is contradicted by the two reports on mortality released by Statistics South Africa (2002 and 2005) as well as Mbewu's own scientists at the MRC who published a mortality report in 2002 demonstrating that the increase in adult mortality is due to HIV and the MRC's burden of disease reports which show that both the numbers of deaths due to HIV and life-years lost due to HIV far exceed cardiac disease, or any other non-HIV related disease in South Africa.

- Mbewu presented on HIV to the Parliamentary Health Portfolio Committee on 16 March 2005. He made the following statements:

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24 Pretoria News, 17/2/2005

“The importance of nutrition in mitigating the impact of HIV and AIDS cannot be understated. The Tanzanian/Harvard University clinical trial by Fawzi et al published recently in the New England Journal of Medicine is a case in point. This blinded, randomised controlled clinical trial showed that amongst over 1000 HIV positive women; those assigned to receive daily multivitamin over the subsequent 5 years showed a 30% reduction in death and progression to AIDS compared to those who did not receive multivitamin. This implies that multivitamins can reduce the socioeconomic impact of HIV and AIDS by both reducing the annual death rate, as well as reducing the rate at which patients deteriorate to the point of needing active medical care.

In addition, the widespread use of traditional medicines in AIDS could have direct benefit, if efficacious in reducing mortality; as well as indirect benefit in stimulating the industry of producing and distributing natural medicines.”

He further stated

“*Little is known about the length of survival of patients on antiretroviral therapy in resource poor settings. Data from ACTG studies in the USA, using regimens similar to those we use in South Africa suggest that median survival once started on ARVs is likely to be of the order of several years but this is very tentative.“*

These statements are misleading. He has contrasted multivitamins with antiretrovirals and in effect argued that there is more reliable evidence of the usefulness of multivitamins than antiretrovirals. This is false. The opposite is actually the case. Little is known of the effect of multivitamins on people with HIV. While Mbewu correctly identifies that a Tanzanian study found them to be beneficial, he fails to point out that these benefits were small relative to antiretrovirals. He claims little *“is known about the length of survival of patients on antiretroviral therapy in resource poor settings”*, while actually little is known about the survival benefits of multivitamins and a lot is known about the survival benefits of antiretrovirals in resource-poor settings. A number of studies from Africa have been published demonstrating increased survival due to antiretrovirals and antiretroviral trials have been conducted in South Africa demonstrating substantial survival benefit. The point however is that the two interventions are not mutually exclusive. Patients with HIV should be provided with the multivitamin supplement used in the Tanzanian study. They should also be able to access antiretroviral treatment when necessary.

The pseudo-scientific statements by Mbewu challenge our confidence in the MRC's continued academic independence.

- The timetable of the Operational Plan has never been published. The Department of Health has never said whether there is in fact a timetable and claims that Annexure A (the timetable referred to in the Operational

Plan) was only ever a draft, a claim we find implausible (see above for details of the court action on this that took place and resulted in a punitive cost order against the Minister of Health). If there is no timetable, this is disastrous and unconstitutional as it would be unreasonable administrative action to implement a programme without one. If there is a timetable, it should now be released.

The above record is partial; there are many other instances of poor governance on HIV.

[ENDS]