AIDS DURBAN 2000-2016

PETER PIOT + MARK HEYWOOD + EDWIN CAMERON + SALIM ABDOOL KARIM + HOosen COOvADIA + LINDA GAIL BEKKER + ROBIN WOOD + FRANCOISE BARRÉ-SINOuSSE + GLEnDA GRAY + QUARRAISHA ABDOOL-KARIM + JAMES McINTYRE + TUlu ONI + FRANCOIS VENTER + LYNN MORRIS + CAROLYN WILLIAMSON + KATHY MNGADI + AARON MOTSOALEDI + VUYISEKA DUBULA + FAREED ABDULLAH + SHARONANN LYNCH + ANELE YAWA + CHRIS BEYRER + LEIGH JOHNSON + POLLY CLAYDEN + SIMON COLLINS + SHARON LEWIN + KERRY CULLINAN + KANYA NDAKI

incorporating the NSP Review Edition #15 – July 2016
Long-time HIV clinician and scientist Professor Francois Venter gives a comprehensive and frank assessment of the epidemic – Read this for your one stop shop before you enter the Durban 2016 maze. Page 11

The National Strategic Plan for HIV, STIs and TB set a number of targets to be met by 2016. We track South Africa’s progress in the latest edition of our popular indicator table. Page 120

Leading epidemiologist Dr Leigh Johnson assesses what mathematical models are telling us about the prospects for HIV elimination and reaching the 90-90-90 targets. Page 105

The province of KwaZulu-Natal is often lauded as an example of how to deal with the HIV epidemic. This feature scratches below the surface and finds that all is not well. Page 50

Free State: A collapsing health system overseen by an NEC who is facing a slew of corruption charges. We continue our focus on this beleaguered province and the Community Health Worker Crisis. Page 64

While the struggle for affordable HIV medicines has largely been won, the same is not true for medicines to treat hepatitis C, diabetes, drug-resistant tuberculosis and various forms of cancer. Page 97

In this issue
TOP 10 ASKS FROM DURBAN
HIV AND TB IN SOUTH AFRICA

Despite huge progress since the end of AIDS denialism, only about half of the people who should be on antiretroviral treatment in South Africa are receiving treatment in 2016. HIV incidence remains stubbornly high (over 300 000 new infections per year) and TB continues to kill tens of thousands per year (estimates vary quite widely). HIV and TB is clearly still a crisis.

Based on the articles in this edition of Spotlight and on the recent work of the Treatment Action Campaign and SECTION27 we have compiled a list of the top ten priorities for the HIV and TB response in South Africa. While not everyone will agree with everything, we have tried to make a list most people would agree with.

1. All provincial MECs (ministers) for Health, heads of provincial health departments, and others holding key posts in the public healthcare system, who are implicated in corruption, lack relevant qualifications, or lack commitment to public service must be dismissed immediately.

2. Before World AIDS Day 2016 government must publish a comprehensive and fully budgeted for plan to provide all people living with HIV in South Africa with a reliable supply of quality antiretroviral treatment.

3. The Department of Health must launch an ambitious new HIV Counselling and Testing campaign before the end of 2016 to ensure that everyone knows their HIV status. Steps must be taken to prevent coerced testing.

4. The Department of Health must ensure that all schools provide comprehensive HIV and sex education and easy access to condoms from the beginning of the 2017 school year. Whether or not this commitment delivers on this will be a key test of its commitment to reducing the rate of HIV infections in young women.

5. South Africa must triple its investment in TB R&D and pressure other high TB burden countries to do the same – especially other BRICS countries. South Africa must also take the lead in advocating for an R&D treaty or agreement at the World Health Organisation and must play a leading role in UN processes reassessing the way in which society pays for medical R&D.

6. South Africa must urgently amend its patent laws so that we can utilize public health safeguards available to us under international law.

7. Government (not just the Department of Health) must conduct a survey of all TB facilities in all public facilities – including clinics, home affairs offices, police stations, and correctional facilities. This must be followed by an ambitious national TB infection control campaign.

8. The Department of Health must ensure that a large national scale-up of TB is fully implemented in the healthcare system in all provinces before the end of 2017.

9. Donors must ring-fence at least 2% of all funds flowing into South Africa for supporting independent civil society. Without civil society to hold government to account and to build treatment literacy in communities South Africa’s AIDS response will fail.

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This then is our objective – through collecting and summarising evidence, through serious analysis and reflection, through quality journalism, and by investigating and reporting on what is happening at the coalface of healthcare delivery – we intend to provide the information that will help fuel a more active and ambitious political response to HIV and TB.
A collection of HIV activists, scientists, researchers, bureaucrats, academics and global leaders reflect on 16 years of an epidemic. Some have opted to make it personal and some angry while others have kept it clinical. We invite readers to join us on a journey which started in Durban in 2000, paused in Toronto in 2006 and has returned to the coal face of the epidemic.
Our house is still burning: We need your help

Anele Yawa

What is the state of play as the world returns to Durban 16 years after the historic 2000 AIDS conference? It is simple: less than half of people who need HIV treatment have access to it.

Around 17 million people living with HIV are receiving antiretroviral therapy, 20 million are not. We now know that 20 million people are at increased risk of developing tuberculosis and cancers – even if some of them still have high CD4 counts. We also know that providing those 20 million people with treatment will help prevent many new HIV infections. It is clear what we need to do: we need to make sure an additional 20 million people have access to treatment. On this score most of the researchers, doctors, diplomats, policy-makers and activists gathering in Durban will agree. We have all the slogans and all the right rhetoric. We all agree that 90-90-90 is the way to go.

But 20 million? Twenty million when all we’ve achieved so far is 17 million – and that 17 million only through years of struggle, sweat and tears, with years of donor assistance, and unprecedented political will. Is it not madness to think of donor assistance, and unprecedented efforts, and to have easy access to condoms?”

Getting serious means addressing the political obstacles to fixing our healthcare systems. It means dealing with corruption, mismanagement and patronage in our healthcare systems. It means not turning a blind eye when healthcare systems are wrecked by people who are politically well-connected – as is happening in the Free State province here in South Africa. It also means challenging that while PEPFAR gives, the United States Trade Representative taketh away – the latter by bullying poor countries into trade deals that compromise access to medicines.

Getting serious also means not tiptoeing around cruel and inhuman legislation such as the anti-gay laws in place in many countries. At a conference like the International AIDS Conference IAC, we must say loudly and clearly that what countries like Nigeria and Uganda are doing is unacceptable and an affront to our common humanity.

Getting serious means an end to empty rhetoric and spin. It means that UNAIDS must stop talking about an end to AIDS while there are 20 million people who still need treatment. We cannot spread complacency just because we want to tell a positive story. Our lives are not an advertising campaign.

At this point in the AIDS response, complacency is our greatest enemy. Even though a staggering 20 million people still need treatment, we have allowed the spotlight to shift. We have allowed the world to think AIDS is no longer a crisis. To the extent that we have allowed this to happen, we have betrayed the 20 million people needing treatment today.

We have no choice. We are morally obliged to change this in Durban.

Getting an extra 20 million people on treatment will not be easy. If we are ever to get near an end to AIDS, then we have to rock the boat. I know that most of us want to be polite and not offend anyone. But our moral obligation is not to ourselves, or our own comfort, but to the 20 million people who still need treatment. We have no choice. We are morally obliged to change this in Durban.

We must demand that HIV and TB is on the top of the agenda when the G7 or G20 meet. We must demand that more money is invested in TB research. We must say no to a world where the United States government spends US$600-billion a year on its military, but the entire world can only find US$700-million per year for TB research.

We don’t have to go hat-in-hand to Geneva or New York. We don’t have to accept ‘no’ for an answer. If a house is burning with people inside, then we help. That is what it means to be human.
Activism and Civil society: what it is and what it’s not

Mark Heywood

2016 is a year of AIDS anniversaries. • It is the 20th anniversary of the International AIDS Conference in Vancouver where Nelson Mandela defied Thabo Mbeki noting that “in the face of the grave threat posed by HIV/AIDS, we have to rise above our differences and combine our efforts to save our people” and calling for “large-scale actions to prevent mother-to-child transmission”. • It is the sixteenth anniversary of the Conference in Durban where Nelson Mandela and the UNAIDS-Lancet Commission report Defining AIDS – Advancing Global Health * where it is stated: “Activism constitutes a global public good, deserving investment commensurate with the role it plays in improving health outcomes. The independent, sometimes confrontational, legacy of activism should be revitalized and nurtured because it provides political incentives for attention and support to AIDS and health.” (my emphasis)

The report also recognises that: “A global health movement can transform a lofty set of global goals into community realization. Civil society actors will need to find new ways to organise activism, while governments and international organisations must create conditions for activism – including direct investments, a free and open media, protection of rights to speech, and assembly to raise inconvenient truths – be they related to emerging pandemics or environmental health issues.”

But what is activism? And what is independent? In fact, what is this mysterious creature called civil society that everyone talks about? These questions need honest answers. They are also crucial in the context of a growing recognition by some donors, PEPFAR included, that activism must be funded. They need honest answers because in recent years the smell of dollars and perfumes has drawn a range of charlatans under the broad umbrella of civil society. Frequently these are people whose actions and motives cause division and conflict within communities as well as amongst governments and donors. They are also a waste of money.

So how to distinguish independent activism from its pretenders? I would argue that it has five intrinsic characteristics:

1. It is connected to impoverished and marginalized communities – the people still most at risk of HIV and AIDS. It does not usurp the voice of these communities but empowers and amplifies it. Activists come from them and constantly return to their communities. They should be seen to be accountable, mandated and to share what they learn (and what they earn).

2. Activists are self-sacrificing rather than self-advertising. They do not use their positions to solicit jobs or cosy-up to power.

3. Activism is not a job. But it must be professional. Activists are thirty for knowledge that can advance our cause, we follow evidence and base advocacy on facts.

4. Independence means not being beholden to a particular donor or power, public or private. It means independence from private companies and from governments, the willingness to speak out without fear or favour. Activists are not anti-government. In fact we try our best to build effective governments because governments have the power and the duty to save our lives and ensure our dignity. But democracy is our oxygen and we will protect or fight for it.

5. Activism is based on the continuous promotion of human rights, equality and social justice. This is not only something it does externally, but it must live its practice. It can’t tolerate racism, sexism or homophobia.

Put simply: Independent civil society activism is vital to the success of ending AIDS. It’s crucial to 90-90-90. Let’s put it another way: the world will not end AIDS or TB without activism.

But what is activism? And what is independent? In fact what is this mysterious creature called civil society that everyone talks about?

• It likes proximity to political power. It seeks public stages and photo opportunities, mainly to secure attention and support to AIDS and TB, in the eyes of the ordinary people. It is about ensuring that AIDS money is spent on AIDS. Civil society must accept and embrace the same standards that we demand of others, particularly transparency and accountability. We call for an activist Code of Conduct, developed by ourselves, that donors can use as a basis of assessment.

• TAC believes we have done our best for the last 17 years to hold ourselves to these standards. We are not without fault and we have not avoided mistakes. But when we encountered corruption in our ranks we expelled it. We have maintained openness. Our books have been audited every year. Our leaders remain elected and accountable to our members. Our organization is open for inspection. We call on all civil society organisations to embrace this standard.
“The end of AIDS” tune is premature and dangerous

Professor Francois Venter

It is strange to think of the progress we have made as a country since 2004, when the South African antiretroviral (ARV) programme rollout was started.

The success of the programme has been beyond some of our wildest dreams. A situation, where almost half a million people were dying every year, has been transformed. Over three million people are on safe treatment, life expectancy is up across the country (life expectancy is normal for people starting ARVs with CD4 counts above 350), and mother-to-child transmission has plummeted. The steps to accomplish this have been astounding, when you think about it – rolling out HIV testing, getting people “staged” with CD4 counts, transitioning them to adherence interventions to get them started on ARVs, and keeping them in care, while reliably supplying the drugs and laboratory monitoring services.

The government has received much applause, both locally and internationally, for sustained political and financial support to the HIV programme since 2008, making it one of the few non-donor dependent programmes in Africa. The UNAIDS 90-90-90 targets have been embraced by the Department of Health as aspirational targets, and seem tantalisingly close. Data from the Africa Centre shows clear correlation with ARV coverage, and a decrease in new HIV infections. For the first time in decades, we have seen a decrease in TB numbers, almost certainly due to increased coverage of ARVs. All this, in a health system that can charitably be called less than optimal.

There are brave government officials who stood up during the denialist Mbeki administration period, who fought hard for a scientific approach, where cabinet did little to challenge their irrational President and his obdurate Minister of Health. Many of these same officials stayed on, and have supported the Zuma administration and current Health Minister Aaron Motsoaledi in giving us the world’s largest ARV programme. There are many unsung heroes in the struggle against AIDS denialism, and hopefully one day their story will be told.

However, to quote an old revolutionary: “Tell no lies… Claim no easy victories”. We face huge challenges with sustaining the HIV response in South Africa, and we should not kid ourselves that the road to getting on top of the epidemic is even half-done.

The rhetoric of agencies, suggesting the end of AIDS is around the corner, is grossly premature and very dangerous.

Two critical and vastly different factors have played a part in making our HIV response so effective:

- Unprecedented community and civil society mobilisation. Led by the TAC, and quietly supported by many in government, the clashes with the state and the pharmaceutical industry kept the fight for better treatment front and centre of the AIDS response since 2000. Aided by researchers, clinicians, donors and a critical media, apathy on the part of the public was transformed into outrage at government’s initial denialism and subsequent anaemic support under Mbeki. Less acknowledged was the huge amount of community treatment literacy that was undertaken by civil society that prepared patients at a local and clinic level for taking treatment.

- Resilience of ARVs. The spectre of mass ARV resistance and poor adherence never materialised. While ARV resistance is devastating at an individual level, and there may be a signal that certain drug classes now may have slightly increased.

UNAIDS released data showing that South Africa has the worst gender imbalance in terms of access to ART in the world.

Money

The budget for the HIV response is huge in absolute terms. While certainly appropriate considering the burden of disease, and the effectiveness of ARVs, the fact that the National Treasury largely finances the programme makes it vulnerable to economic downturns, currency fluctuations and political distractions, means that trying to fix current problems is probably too ambitious. The national ARV bill will be over R10 billion by 2018; removing CD4 counts as an initiation criteria and testing everyone will drive it higher.

Get to the workplace and get creative

Some quick wins seem possible – male representation in the workplace far exceeds women’s, this is an easy place to start, perhaps with the HIV-testing programmes discussed above. In addition, expanding clinic times to accommodate working people seems sensible. However, this does not reach unemployed men, a huge number of people. Self-testing has been shown to be very acceptable to men, but finding acceptable and validated tests will probably only occur next year, and may take time to enter the state sector. New and creative ways of accessing men are desperately needed, if any of the 90s are to be attained.

Fix HIV testing quality assurance problems

Finally, an unpleasant elephant in the room is what WHO terms “misdiagnosis”, where incorrect HIV results are given to patients, undermining both testing and treatment programmes. The previous NSP called for the implementation of a single-patient identifier (SPI) for lab specimens, a concept ratified by the national DoH using the national ID number, but very poorly implemented so far. The previous call was on the back of international concern about poor monitoring and evaluation of the programme, and the unknown number of people “lost” to the programme. UNAIDS listed the following as impacts of misdiagnosis:

- Speculum tests may not be done, arguing about the extent of the problem is therefore almost completely speculative – terms like “lost-to-follow-up”, which often come with implicit stigmatising judgements on patients in systems, are probably more accurately titled “lost from our” (very poor) systems of monitoring. Commonly cited numbers like 30% lost at two years from programmes seem implausible without better data.

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Linkage to care

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Missing in action 1: Men

If the treatment programme is disaggregated by 90-90-90 gender data, South African women are pretty much there, due partly to high testing rates in PMTCT programmes, and familiarity with clinics through contraception and child care clinics (either for the children tested and access ART far less than women. UNAIDS released data showing that South Africa is the worst gender imbalance in terms of access to ART in the world. Men present later and at a lower CD4 count, with poorer outcomes and have poorer adherence in some studies. The rhetoric around young women’s vulnerability to HIV (which is real) obscures the fact that male lifetime risk of HIV approximates women’s – it just occurs over a longer

HIV testing

While HIV testing is reaching a substantial number of people, the 90s knowing they are positive target is the biggest gap in the UNAIDS targets, and the NSP target of testing everyone annually will never be a reality with current testing models. Testing remains stuck in overloaded state facilities or in bureaucratic systems in the private sector.

New testing strategies have not been evident since the dawn of rapid testing over a decade ago, other than the Minister’s major push to test 15 million in 2015. There are lessons in this push, which got huge numbers of people tested and control quality assurance (and a welcome distraction, means that trying to fix current problems is probably too ambitious. The national ARV bill will be over R10 billion by 2018; removing CD4 counts as an initiation criteria and testing everyone will drive it higher.

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Support the NHLS
South Africans may not appreciate what a huge resource a National Health Laboratory Service is (there are few of them anywhere in the world), and how it may assist us in understanding health issues way beyond just HIV. However, the poor support, especially from provinces, that the NHLS has had over the last few years, has severely undermined it. Brave people still work there, and we need it to function efficiently and cost effectively, to get HIV and broader health programmes the lab support they need.

SMS (or WhatsApp) the nation
Innovative cell-phone based approaches also look promising in linking patients to care, but implementation at a mass scale has yet to be implemented. In other fields, such as Home Affairs, there is constant information fed to the public after applications for documents like passports or ID books. Everyone is reminded about their dentist, their car service, or their unpaid Metro bills and traffic fines, and there seems no reason this couldn’t be extended to the public health system to alert patients to appointments, drug shortages, or changing clinic times.

Community engagement
It is hard not to be cynical about support to community organisations. Governments, donors and agencies trumpet at almost every opportunity about how important civil society and community organisations. However, when expenditure is analysed, precious little trickles down to these organisations. As an example, the TAC almost had to close its doors, due to lack of funding, and still battles to find adequate financial support. Communities are tasked with all manner of support to HIV programmes, from education on adherence to palliative care, almost all of it unpaid. Reports of government funding “sweetheart” organisations that do not rock the boat or who are unaccountable, abound. Donors who have supported programmes that publicly criticise or embarrass government, often with good cause, have been berated at times by politicians and officials.

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Set targets for budget allocations
Treatment literacy and community support are acknowledged to be important. In the same way as many budgets have “X percent” allocated to issues such as HIV prevention, a percentage should be allocated for civil society and community support, and monitored as a performance indicator. Those funded should be held to reporting standards seen with other organisations, to ensure accountability.

Novel models of care
MSF have rechristened delivery of drugs, with their (inadvertently misleadingly titled) “adherence clubs”, centralised dispensing points for chronic medications with a strong focus on HIV. However, scale-up of this model has remained challenging, and provincial level buy-in is very variable. In addition, the national DoH have been experimenting with home delivery of chronic medications, although uptake is apparently slow. In Gauteng, vending machines are available on a pilot basis in a limited number of facilities, through a donor programme. The DoH has signalled the urgent need for “decanting” of patients out of busy facilities.

Get innovative chronic disease dispensing to scale
It is heartening to see these new approaches, that both try to decongest facilities, as well as make access more convenient to patients. However, they need to go to scale, as only a small minority of the population currently enjoy access to these new models of care.

Drug stock-outs
Civil society, in partnership with government, has been conducting a regular drug stock-out survey, in conjunction with a problem solving aspect, where reports of stock-outs are rapidly escalated and resolved, often within hours. Despite a rocky start to the relationship, the programme has yielded much information and fruitful collaboration, and two critical lessons:

1. Fixed-dose combination tablets very rarely stock out
This was seen across the country, where stock-outs of adult first-line ARVs and TB treatment, both fixed-dose combination, were almost non-existent. Other drugs regularly stocked out, and despite (often heroic) problem solving by health care staff to get these medications, stock-outs of ARVs in alternative regimens and for children were common. This needs careful consideration by guideline committees, when considering regimens, especially for children, where alignment with the adult FDC would protect them from individual stock-outs.

2. Don’t discount verticalised services
These are lofted by many health managers, who prefer the simplicity one-size-fits-all model of primary care. Unfortunately, it seems that for certain marginalised or smaller groups, this may be the most effective way to address health needs, especially HIV care. Experience with groups like MSM, sex workers and adolescents, as well as pregnant women, suggest that tailored approaches work, and future priority groups like transgender populations are likely to need them too.
**Well-meaning but evidence-free interventions, ranging from meaningless nutritional and exercise advice to mobile mammogram screening, have been adopted by various programme managers, and advocated by senior DoH staff.**

**Missing in action 2:** Young women, men who have sex with men (MSM) and sex workers

Politicians don’t like talking about sex. It’s a vote killer, especially in a conservative country such as South Africa. Unfortunately, young women remain at catastrophic risk of HIV, for reasons we don’t understand, but are likely to be a complex intersection of behaviour, social isolation, lack of gender-based violence, and biology. Interventions that work (condoms, proper sex education that includes access to contraception, and pre-exposure prophylaxis) are not available at schools, despite objective evidence that this is when the vast majority become sexually active, and where substantial HIV and other sexually transmitted disease occurs. Brave moves by the DoH to start extending PrEP services to sex workers and perhaps to MSM, as an HIV prevention plan, are to be applauded, but the same bravery is needed for a much larger segment of society.

DDE needs courage

The Department of Basic Education needs to change its policy, and immediately allow meaningful reproductive education, contraception and condoms into schools. Parent, teacher and politician sensitivities need to be seen in the context of incidence rates of up to 8% at some of the KwaZulu-Natal sites.

Politicians need to change laws

In tandem, the excellent progress made by a partnership of the DoH and a wide slew of civil society organisations to address the health needs of sex workers in the new plan, which includes a focus on HIV prevention with immediate treatment and PrEP, is undermined by the continued criminalisation of sex work, with harassment by the police a daily reality. Again, it will take brave leadership to address this, but it is necessary.

**Missing in action 3:** Civil society and business

The Mbeki era currency distracted us, and let a huge portion of our society off the hook on the AIDS response. Beyond a few public statements by leaders from the churches, unions, and within business, precious little of substance has come from these groups (with the exception of some home-based care groups, and some work-based treatment programmes).

Set them a challenge

Challenges need to be issued across all these groups, to support the HIV response. Again, a national HIV testing programme would be a tangible expression of this, linked to accountable targets.

Distractions

It’s important to focus on what is important within the HIV programme. Much airtime has been given to the so-called “non-communicable disease”, both within the general health system and within HIV programmes. These conditions are on the increase and are by no means limited to South African populations, with increasing questions about the epidemic among young women, and legal challenges to sex worker legislation are required. However, other interventions would help.

**Support PrEP**

Pre-exposure prophylaxis is complex, but it works. The current push is appropriate, but the group who most needs it, young women, will almost certainly not receive it using current models of care. It will need comprehensive HIV testing and other programmes will require drive and creativity.

**Support vaccine development**

This is a long-term solution, but is looking more promising than a few years ago.

**Stop getting distracted**

Politicians are obsessed with people’s sex lives, disregarding home-grown evidence and insisting on supporting poorly thought-through programmes around concurrency and sugar daddies. We need to focus on better relationships, gender violence and attention to condoms provision and reproductive health, not billboards trumpeting back-up sex-education messages about what we have sex with.

**“Hide nothing from the masses of our people. Tell no lies. Expose lies whenever they are told. Mask no difficulties, mistakes, failures. Claim no easy victories…”**

– Amílcar Cabral

**Conclusions**

Amílcar Cabral was a Guinea-Bissauan and Mozambican politician, Marxist agronomical engineer, writer, and a nationalist thinker and political leader. He was also one of Africa’s foremost anti-colonial leaders (Wikipedia).

The full revolutionary quote by Cabral I referred to earlier in this article is: “Hide nothing from the masses of our people. Tell no lies. Expose lies whenever they are told. Mask no difficulties, mistakes, failures. Claim no easy victories…” We can’t get complacent, with the empty promise from agencies of an “AIDS-free generation” when our victories (in some cases) have been relatively easy, and many mistakes were dismissed. Many of these problems (and solutions) are not specific to HIV. But HIV has allowed the whole area of health to be ambitious again, reconnecting with the energy that briefly arose after the Alma Ata Declaration on primary health care, and perhaps with more critical reflection (and resources to support it). It is an exciting time to be in the health field, especially in HIV, and people in South Africa rely on us to get it right.

**Professor Francois Venter** is the Deputy Executive at Wits Reproductive Health & HIV Institute, Professor in the Department of Medicine at the University of the Witwatersrand.

**CONFLICT OF INTEREST DECLARATION**

Prof Venter receives support to both his salary and programmes from a large number of donors, as well as from the pharmaceutical industry (including drug donations to research projects) and managed care organisations. He currently turns a large sex worker health programme, an HIV self-testing programme, and is working on research studies on the new drugs detailed above, as well as a programme looking at non-communicable diseases. The views expressed here are not necessarily of his organisation.

Durban: From AIDS 2000 to AIDS 2016

Professor Salim S. Abdool Karim & Professor Quarraisha Abdool Karim

AIDS Conferences are unique in being a cross between a scientific meeting and a community engagement forum. People from all walks of life attend these meetings and they are a far cry from the usual rigid structure in scientific conferences in order to cater for the range of interests.

As a result, there are plays, movies, music concerts, art exhibitions, marches, poster protests, stump talks in the community village and other events in the midst of presentations on, for instance, the conformational structure of gp41 on the outer envelope of the virus.

The International AIDS Conference in Durban in 2000 was all this plus a lot more. It created a unique belief that we could collectively change the world and created a common purpose to do just that by doing whatever it took to bring AIDS treatment to all those who needed it. Critically, scientists and clinicians walked alongside activists, artists, drug company executives, policy makers, front line health care workers, political leaders, clergy, judges and just ordinary people to say altogether that the global inequity in AIDS treatment can no longer be tolerated and that it must change. Each person chipped away at the edifice of inequality and collectively achieved the goal of bringing down the wall of inequity as the prices of the drugs were brought down and international solidarity led to funding becoming available to provide treatment to all those who could not afford it.

Winning the bid to host AIDS 2000 in Durban

Following the establishment of democracy in South Africa in 1994, Quarraisha Abdool Karim was appointed as the Head of the country’s AIDS control programme. At the time, she was also a member of the International AIDS Society’s (IAS) governing council and proposed Durban as a venue for the AIDS Conference in 2000. To create a group to work on the bid, she called a meeting in Pretoria at which Hoosen (Jerry) Coovadia was appointed to lead the conference with Salim Abdool Karim as its Scientific Chair and Gustaaf Wolvaardt as its lead organiser. The team quickly prepared the bid documents and Quarraisha obtained the $1 million guarantee from government just in time to lodge the bid.

There was one small snag – Durban did not have a functioning conference centre yet – it was still under construction on the site of the old Durban central prison. There were many naysayers who were concerned that the conference had never been held outside the developed world and that a developing country would not cope with the demands for such a big meeting. There were also those who raised their concerns about the safety of delegates, in response to information doing the rounds about crime in Durban and political turmoil in some parts of South Africa. The most cutting of these criticisms was that the “big name” laboratory scientists would not attend a meeting held in South Africa. Well, none of these criticisms turned out to be warranted, as we now know and, thankfully, several of the senior leaders in the IAS, including Stefano Vella, Mark Wainberg, and IAS Secretary-General, Lars Kallings strongly supported the bid. Once the bid made it to the final stages, Lars Kallings undertook the site visit. The shortcomings in the bid could no longer be kept out-of-sight; they were now glaring! For example, Quarraisha walked Lars around the Durban International Conference Centre (ICC) building site in hard hats, imploring Lars to use his imagination to ‘see’ that the Conference Centre would be able to cope. A bigger snag then emerged. Durban did not have the required number of five- and four-star hotel rooms – it took Gustaaf’s stroke of genius to solve this problem with his proposal to have two large luxury liners docked in Durban harbour – just 10 minutes from the Conference Centre – for the week of the conference. For every shortcoming and problem that emerged, yet more imaginative solutions were found. Eventually, we got the good news from Lars that the bid had been successful.

Then the hard work of organising the conference starts

Gustaaf was tasked with creating the organisational infrastructure (offices, staff, telephones, vehicles etc) and thus the non-profit company Dira Singwe Conferences was born with the members of the South African conference committee as Directors. Right from...
the start, the team was committed to drumming as a theme – the local animal skin drum felt and sounded African and the team was teeming with ideas on how to use the drum image, drum logo, drum sound and actual collective drumming in the conference. We were initially hesitant as it did not seem appropriate for a scientific meeting but we were totally sold on it after attending a drumming session arranged by Gustaaf at the ICC. We saw a dozen different ways in which the drum could be used in the conference. To give the drum a genuine South African look, it was covered in Ndebele design. Similarly, the word “AIDS” in the conference logo was coloured in the unmistakable Ndebele design and colours – a great looking logo emerged with a distinct African flavour.

Organising the conference was sometimes challenging. There were too many different constituencies to satisfy. Committee meetings were imbued with strong political overtones while discussions on the scientific content rarely featured except when it came to heavyweights who were invited to speak. A rapidly emerging problem was the political situation with concern about the 1999 South African elections and concerns that the country may be in turmoil post-Mandela. Fortunately, none of these concerns materialised – Durban was reached safely and peace was all the way through. The transitional period to President Mbeki went smoothly and peacefully. Little did we know that South Africa’s real challenge was lurking – AIDS denialism.

Mbeki and AIDS denialism Mbeki had proved himself to be a powerful orator and intellectual in his “I am an African” speech at the adoption of the Constitution by South Africa’s Parliament. However, shortly after his election as President, a Jekyll-like side emerged – one characterised by an obsession with politics over public health, especially when he had read our public comments and statements challenging Mbeki, thereby incurring her wrath against the conference. The stage was set for global AIDS treatment. The conference itself became a melting pot for many ideas and opportunities. The conference’s unique interactions – drug company representatives were speaking at community forums in the Conference Village – gave them the chance to make commitments to affordable treatment; healthcare providers explained the pain of watching their AIDS patients die helpless in their beds; drug companies talked about the opportunity to ease suffering and community voices

Inevitably, those associated with the AIDS 2000 conference came under attack from Tshabalala-Msimang, especially when she had read our public comments and statements challenging Mbeki, thereby incurring her wrath against the conference. Conference delegates were carefully shepherded to the chairs on the playing field while the general public took over the stadium’s raked seating in their thousands. The funding for the theatrical opening session came from a generous philanthropy and what a spectacle it turned out to be. Flying acrobats and a choir with over 1 000 singers – almost every church choir in Durban was roped in – all in regal costumes pouring forth amazing renditions. We were worried about this grand opening, but everything was going along well – until Mbeki spoke. He rambled on quoting an out-of-date WHO report that said that AIDS was not a major health problem and proceeded to lecture the thousands of AIDS patients, activists, health care providers and researchers that AIDS should not be our country’s and the world’s priority. A husky descended with palpable disappointment in Mbeki, turning rapidly into anger. The audience was bristling with disbelieve at Mbeki ended. However, none of these concerns materialised – the elections were peaceful and the transition to President Mbeki went smoothly and peacefully. Little did we know that South Africa’s real challenge was lurking – AIDS denialism.

The vibrancy of 2000 is no more. It has been replaced with calm and rational options for the future of the HIV epidemic made possible by a combination of scientific discovery, innovative funding mechanisms and deep commitments from policy makers, activists, researchers, health care providers and many others to make AIDS treatment available.

PROFESSOR SALIM S. ABDOOL KARIM is the Director of the Centre for the AIDS Programme of Research in South Africa and Professor of Clinical Epidemiology at the Mailman School of Public Health at Columbia University. PROFESSOR QUARRAISHA ABDOL KARIM is Associate Scientific Director of the Centre for the AIDS Programme of Research in South Africa, Professor of Clinical Epidemiology at the Mailman School of Public Health, Columbia University.
South Africa on the front foot and moving forwards

Professor Linda-Gail Bekker & Professor Robin Wood

The June 2000 UNAIDS global report on AIDS painted a sombre picture: already South Africa had the greatest number of people living with HIV than any other country in the world and life expectancy had fallen rapidly to historical levels.

And yet as the world convened at the International AIDS Conference in Durban in 2000, the first time such a global convening had occurred on African soil, we already knew that combination antiretroviral therapy (ART) was highly effective in reducing AIDS and death. But these life-saving drugs were unavailable to the majority of the 5 million South Africans living HIV because of their cost, and a political administration in AIDS denial. Hospitals throughout South Africa were full of dying patients, most of them young and in the prime of life.

Our greatest challenges then to counteract the devastation that was unfolding included the lack of national political will, with a President who openly supported fringe denialist theories and a health minister who advocated for traditional remedies and was outspoken about her negative beliefs on antiretroviral therapies. Other challenges that undermined individual benefit from antiretroviral therapy included adherence to difficult regimens and was otherbooked by her negative beliefs on antiretroviral therapies.

The need for universal coverage continues to challenge the national health budget, the ingenuity and the innovation of the South African health care sector. Universal testing, treatment and prevention has exposed our inability to reach the difficult-to-reach populations in South Africa. Durability of treatment will be tested as individuals continue to be tracked and third decades of ART. Inadequate health seeking behaviours, social mobility and overextended health facilities present real challenges to tracking individuals in the epidemic and our efforts to fully extend treatment. The need not only to reach enormous numbers of individuals and to ensure their retention and viral suppression in care exposes the weaknesses and increases pressures on our health care system.

There is increased recognition that epidemic control will remain elusive without interruption of transmission in the highest incidence settings. This will require additional resources and galvanizing an already stretched health system to fill these gaps, as well as mobilisation of communities well beyond health facilities. This extent of scale-up of treatment and prevention raises questions of funding and supply. The lack of international focus due to competing global health and other perceived social and political needs begs the urgent question of how these efforts will be funded through an already overstretched national fiscus alone.

In 2000, South Africa, despite its substantial role in the global epidemic, found itself on the back foot in terms of our response and our contribution. Many were confused by the mixed messages emanating from the Department of Health in Pretoria. Despite this, the message of Durban 2000 and the Durban Declaration spurred civil society, international agencies and individuals to unite around a common treatment goal. The picture happily looks very different in 2016. The challenge facing us now as we contemplate again the arrival of many thousands of delegates to Durban for the 21st International AIDS Conference, is how to translate the transformational benefits of individual HIV care and prevention into population benefits. The need for universal coverage to realise population benefits...
How HIV shaped us

Professor Glenda Gray & Professor James A. McIntyre

HIV changed the nature of health in South Africa as our new democracy emerged. Seemingly overnight, in front of our eyes, young people and children died in unprecedented numbers. HIV slashed life expectancy, wiped out a generation of economically active adults in their prime across sub-Saharan Africa, reversed gains in under-five mortality and created a cohort of AIDS orphans. It also revealed the inter-relatedness between social behaviour, stigmatisation, cultural mores, religious beliefs and human health. HIV changed our society at a time when South Africa needed no distraction as it battled to rebuild a nation post-apartheid.

From 1998 to 2003, civil society together with AIDS activists, doctors and scientists used scientific evidence, in the face of government AIDS denialism, to force the use of antiretrovirals for the prevention of mother to child transmission of HIV-1, and subsequently the roll out of antiretrovirals as life-saving treatment. Our work at the Perinatal HIV Research Unit (PHRU) in Soweto was the subject of intense media controversies. We had established the PHRU when we commenced research into the prevention of mother to child transmission of HIV-1 (PMTCT). Initially, we evaluated interventions to minimise breast milk transmission of HIV-1, before embarking upon the PETRA study, one of the first antiretroviral perinatal transmission studies to be conducted after the famous USA ACTG 076 study, which demonstrated that AZT could reduce perinatal transmission significantly. Because of our involvement in the management and care of affected pregnant women and their infants, we became one of the first public sector sites to conduct antiretroviral treatment trials in adults and children. This gave us the necessary comfort to propagate the use of antiretrovirals in Soweto. Soweto, thus became one of the first demonstration projects for both PMTCT and ARV treatment roll-out, funded by the French government’s Fonds de Solidarité Thérapeutique International (FSTI) in a direct grant to the PHRU.

This Demonstration of Antiretroviral Treatment (DART) was approved under strict conditions by the then Minister of Health, Dr Manto Tshabalala-Molema. However, as the governmental denialism intensified, our efforts to secure additional funding from the Pangaea Global AIDS Foundation and Clinton Foundation were closed down. We received a phone call from the then AIDS Director at the National Department of Health (NDOH), instructing us to stop developing the proposal, and communication with the donors then stopped without explanation. A decade later, Pangaea acknowledged the South African government pressure to stop working with us.

Political interference at this time was rife and the use of antiretrovirals for PMTCT was seen as an abissive activity. The Castro Hlongwane, Caravans, Cats, Geese, Foot & Mouth and Statistics: HIV/AIDS and the Struggle for the Humanisation of the African document – partly penned by Thabo Mbeki and distributed to ANC branches throughout South Africa – attacked South Africa’s earliest and most prominent AIDS scientists, including Salim Abdool Karim and ourselves. Abdool Karim’s research was characterised as “anti-human” promoted by “corporate forces” and we were singled out, because of our work using antiretrovirals for preventing mother-to-child transmission of HIV, as “killers of Black Women”. In 1999, results from a study in Uganda, showed that a single dose of nevirapine given to HIV-1 infected pregnant women in labour and a dose administered to their infants within 72 hours could reduce PMTCT. These results galvanised us to try and secure this nevirapine-based intervention for HIV-1 infected women in our clinic, and we relied on donations to keep a steady supply before nevirapine was officially available for PMTCT. We supplied nevirapine under tense conditions at the Chris Hani Baragwanath Hospital. One day, a doctor from a peripheral hospital phoned, asking us to supply nevirapine to a HIV-infected woman in labour. He sent an ambulance to the PHRU. We gave the driver the nevirapine tablet and syrup, only to be phoned by the hospital superintendent admonishing us, as he barred this pregnant woman from access to a drug proven to be efficacious, effectively allowing HIV exposure during birth without prophylaxis. In 2001, government policy changed under pressure mounting from civil society as well as political pressure within the political-government structures. In an era where the cost of drugs was declining, we were fortunate beneficiaries of USAID and Elizabeth Glaser Pediatric AIDS Foundation funding that enabled us to scale up treatment in Soweto. In a space of six months, our team, led by Dr Leorah Mohapi, put just under 1 000 people in treatment, and our PMTCT programme directed by Dr Avy Violari, expanded in Soweto, accelerating access by opening PMTCT programmes in every antenatal clinic. Even though we were involved with rolling out care, and scaling up interventions for maximum impact, we knew we also had to focus on the clinical science, and designed a number of programmes, which were funded under the Clinica SA banner. Studies under this programme impacted on international guidelines that revolutionised treatment management for infants, as well as defining that antiretroviral treatment could be executed by nurses instead of doctors. The Children with HIV Early Antiretroviral (CHER) study, undertaken at the Chris Hani Baragwanath and Tygerberg Hospitals showed that early treatment in HIV-infected infants could significantly reduce deaths. The CHER-SA study demonstrating that ARV care could be task-shifted to nurses allowed for the mass roll out of treatment in South Africa and beyond. We continued with PMTCT research which continued to help elucidate and refine regimens to make them more potent, the requirement to eliminate paediatric HIV. Knowing that the only effective way to control the HIV epidemic was through prevention, the PHRU expanded its focus beyond PMTCT and ARV treatment for adults and children.

At this time the South African AIDS Vaccine Initiative was established, and Glenda Gray played a key role in helping to design and implement a new treatment from prevention. Tailed with taking the South African developed HIV vaccine candidates into first-in-man studies, both in South Africa and the US, Gray would embark on leading vaccine trials in South Africa. For the past decade, finding an effective vaccine has been the fixation of most of Gray’s clinical research. James Gray has had to learn to continue to fine-tune innovation to take interventions to scale, turned to implementing the wide-spread roll out of treatment and PMTCT programmes. Concerned by the huge burden of HIV amongst men who have sex with men (MSM) and the lack of appropriate treatment for MSM in the public sector, McIntyre pioneered the development of MSM services in South Africa, that have become a model for both prevention and treatment. Now, just over a decade and a half after the International AIDS Conference in 2000, South Africa’s burden of disease estimates indicate a nine-year increase in the average life expectancy from an all-time low in 2005, where total life expectancy was under 55 years. Our under-five mortality has been slashed by half from 80/1000 to 40/1000. Similarly spectacular gains have been made in infant mortality rates from 54/1000 to just under 30/1000. Maternal deaths have declined from 190 to 155/100 000. Most of this is attributed to our scale up of antiretrovirals in the public sector. These spectacular gains made by South Africa are a tribute to the activists, health care workers and scientists, who, faced with a horrific epidemic, did the right thing, and “en masse” spoke truth to power, and were relentless in their pursuit of scientific evidence and ruthless in their implementation of that. To have been part of this, is a humbling experience, and see how much progress has been made is gratifying. Now we have to ensure that the lessons garnered in our experience with the HIV epidemic, are encapsulated in the quadruple burden of disease and the interconnecting epidemics of communicable and non-communicable diseases; maternal and child mortality; and infection and injury.

Soweto, thus became one of the first demonstration projects for both PMTCT and ARV treatment roll-out...
HIV and non-communicable diseases: a dangerous partnership

Dr Tolu Oni

WHAT: Evolution of the HIV epidemic

Over the years, HIV and the ensuing global epidemic has resulted in millions of deaths. With the advent of antiretroviral therapy, and the advocacy efforts of civil society, HIV-related mortality has significantly decreased, as has mother-to-child transmission.

Consequently, a worldwide epidemic has been characterised by fear, illness and death, which has transformed with HIV-infected patients now able to live longer in good health in settings where antiretroviral therapy (ART) is equitably accessible and initiated early.

The global burden of HIV continues to vary considerably, with a disproportionately high prevalence in sub-Saharan African countries and other low- and middle-income countries (LMIC). In these settings, HIV-related deaths remain unacceptable high, with delays in diagnosis and access to treatment. However, in many LMIC, sustained and expanding provision of ART, at increasingly higher CD4 cut-off values, has resulted in increasing life expectancy and decreasing incidence of new infections.

There is therefore a need to move from a system designed as an emergency response to one of chronic disease management, with an accompanying shift from a predominant morbidity focus to focusing on morbidity (living with HIV and other diseases) and the improvement of quality of life.

WHY: Changing patterns of disease in countries with significant HIV burden

This ongoing evolution of the HIV epidemic towards being considered a chronic disease is occurring against a background of population transition. Many low and middle-income countries are experiencing rapid, unplanned urbanisation, resulting in a significant proportion of urban dwellers living in informal settlements. This changing environment is associated with changing behaviour with decreased physical activity, increased consumption of processed high salt/high sugar foods, increased rates of tobacco smoking and alcohol/substance abuse. This is resulting in an accompanying rise in non-communicable diseases (NCD) such as diabetes and heart disease, and NCD risk factors like obesity and high blood pressure.

Of note, this rise in NCDs is considerably higher in low and middle-income countries. A recent study showed that in South Africa, almost four out of every five people over the age of 50 years has high blood pressure. Another research study conducted in South Africa found that three to four out of every five women are overweight or obese. One research study in South Africa found that among HIV-infected patients attending a clinic for ART, one in five were also on treatment for another chronic disease, predominantly treatment for diabetes and/or high blood pressure.

Given that less than 50% of people with high blood pressure are aware of their diagnosis, this figure is likely to be a gross underestimate, and is on the rise as a greater number of HIV-infected individuals age.

The documentary could have been entitled: “When the world realised they should care about HIV”, as it showed effectively how slow the world was to mobilise to respond to the need for access for all and the consequences of the slow response.

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So many have forgotten

Vuyiseka Dubula

I was just months away from knowing my own HIV status when, in the year 2000, the people took over the streets of Durban marking a revolution to come. Although I was not present in Durban for that year's AIDS conference – I was already connected to the struggle.

This year I will be attending the 2016 AIDS conference. As I reflect on the last decade and a half, I wonder that if Durban was a person, what would I tell her? I would tell Durban that after we left you we continued on a difficult path, one which many of us never thought would happen post-apartheid. I remember the year 2004, for which I have no reason to remind myself of, but I will, because so many have forgotten what it used to be like to march next to someone and then in a few months they are bedridden and dying.

Twelve years ago Francois Louw, an Médecins Sans Frontières (Doctor without Borders) doctor, called me Ntombi yam, not her “patient”, and I called her Magogo, not “doctor”. Then, this family grew as other comrades and doctors became part of my life. Today, I am seen by my nurses sister Nompumelelo Mantangana and sister Lindwe Kotelana. We have become family. I didn’t know any of these hard working health activists before April 2001.

I remember Kabareng Moleketsi, Mandisa Mapugwana, Zoliswa Magwethu, Nomfundiso Soman and many more. Every night my nine-year-old daughter Queen Qhiza, Vuyani Jacobs, Johanna Magwentshu, Nomfundo Somana, Mandisa Magugwana, Zoliswa Nombasa Krune Dumile, Sis Mpumi, Norute Nobola, Yandisa Dubula, Fanelwa Gwashu, Mandla Majola, and Lindwe Kotelana – somehow someone is always there to pick up my medication.

Every night my nine-year-old daughter Nina reminds me that “ndikuphaphela amanzi mama” (should I bring you water mom or have you taken your pills?). My three-year-old son Azania also feels compelled to help me with swallowing them by asking “mama khandiphakazelo ndlakukhoti? (can you please give me a piece)? There are days when I take the six pills without even thinking what they are for – because HIV is not always present in my thoughts.

Twelve years ago I could name many people who lived openly with HIV – not because they wanted attention, but because people like me needed to know we are not alone. Today we hardly know – it’s the same old faces who are now in their late thirties or fourties. We barely talk openly. We are not visible enough to those who just learnt their status.

The world of HIV is moving very fast – we are now talking about controlling the epidemic and ending AIDS by 2030. But I wonder. Our public healthcare system remains the same – it is weak and falling apart. How will we end AIDS? Where is the long promised National Health Insurance? If the space for civil society and funding for civil society is shrinking, who will control AIDS? If NGO’s and social movements are not building from below who will end AIDS? If corruption becomes normalised who will hold those looting from the state accountable?

This is no longer Mbeki’s or apartheid’s fault but the fault of our current government. They too must account for their own misdeeds.

The pills I take twice a day are a reminder of how leaders can sell their people out – how they can commit genocide and go unpunished. It is a reminder of how building poor people’s power is the only weapon we have against the abuse of political power. The pills are a beautiful memory as well as a painful one. The pills I take twice a day are a reminder of how building poor people’s power is the only weapon we have against the abuse of political power. The pills are a beautiful memory as well as a painful one.
Dear Nkosi

Anso Thom

It has been 15 years since you eхаlled for the last time, you would have turned 27 this year. I would imagine it was a relеf—a long breath that spoke of having саrried a heavy burden and responsibility in your much too short life.

I remember how excited you were at traveling to the United States to meet Robin Williams who you said made you laugh. You always loved jokes…you would tell the worst jokes and laugh the loudest. I think that is where my son got his crazy sense of humour from!

Do you remember when you once visited us in Cape Town. You were so sick already and I remember waiting for you at Cape Town International Airport and having to hide my shock at seeing how much you had deteriorated…The crust of thrush sticking thick around your lips, the windbreaker completely dwarфing your frame. You were so excited to be in Cape Town and immediately wanted to go and eat ribs – you ordered the biggest rack of ribs only to stare at it and asking if we could take it home. The thirst was so bad that it was impossible for you to eat most food. The diarrhoeа became so severe that we rushed you to our doctor where she put you on a drip to tide you over even though you should have probably been in hospital.

You loved music so much, one of your favourable soundtracks from The Commitments…You would listen to it over and over again and of course my CD went home with you! Do you remember us going to the Carols by Candlelight at Kirstenbosch? You managed to get us a ride on the golf cart, all the way to the lawns where you lay in our laps, covered in thick blankets and singing each carol at the top of your voice. Your look of amazement and singing each carol at the top of your voice. Your look of amazement when you looked back and saw the sea of candles will always stay with me. Nkosi, on 18 July we will all return to Durban. Some of us are returnees, others are newbies who joined the HIV activist bus along the way. I want to promise you that we will not go to Durban and accept empty rhetoric, lofty promises and articulate but empty political speeches. No, we will go to Durban expecting to live up to your dream where no child is born HIV-positive, no child needs to be separated from their mothers because of disease and poverty and stigma is just an ugly swear word. This will be a conference where the South African government will hear your message, this we owe to you and to the many other children who faced the same fate.

Lala Kukuhle gentle, beautiful warrior, we will feel your presence in Durban we will carry you in our hearts and songs.

All our love, admiration and respect.

Aneo Thom is the Head of Communications at SECTION 27 and an editor of Spotlight.
How the dark age of HIV/AIDS changed our democracy – a personal view

Professor Hoosen Coovadia

I was thrust into the vortex of International AIDS Society’s 13th International AIDS conference in 2000 as chairperson by my close colleagues Professor Quarraisha Abdool-Karim and Dr Gustaaf Wolvaardt, presumably due to the absence of any suitable alternatives, because of my academic record (such as it was at that time) and my leadership roles in the struggle for freedom.

Quarraisha was on the one of International AIDS Society’s highest bodies, the General Council, at the time and had already resigned as head of the Department of Health’s National AIDS programme.

The Durban Conference was the first time the International AIDS Conferences had come out of their comfort zones in the richer parts of the world to a developing country. Though I had never attended an AIDS Conference before, I had an untrammeled view of events at the meeting, for which I had taken a year’s prior sabbatical.

I realise that I was in a privileged position, less for subjective, individual factors, than because of the force and uniqueness of the events swirling around me and sucking me into the white heat of the central controversies. I describe the most striking circumstances, discourses and incidents I witnessed.

Our dark age

I became aware, during the conference, that I was living through a dark age in South Africa’s history of monumental political blunders, some of which, to my utter astonishment, are being reprised over these last few months.

The fairly large themes which underpinned the drama and illustrated the disasters in 2000 included the gratuitous intrusion of government and state institutions in scientific methodology; the impact on a nascent democracy of misguided national policies narrowly based on irrational decision-making; the unforgivable error intrinsic to these policies which negatively influenced health services and caused preventable deaths of thousands of vulnerable people; and finally, attempting to undermine long-established and critical processes in vigilance over the quality of pharmaceutical products.

The very important, practical and life-saving outcomes of the Durban Conference were the establishment of The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and the President’s Emergency Plan for AIDS Relief (PEPFAR) global programmes, which led to an unprecedented global response to the pandemic.

The critical role of activists, globally and locally, in catalysing treatment access, requires its own narrative and is too extensive to include here. However, from my own involvement and my perspective for this paper, centre-stage in this vulgar enactment of those ancient and tragic Greco-Roman and European dramas, and indeed similar global theatre, stands then-President Thabo Mbeki, and his unquestioning acolytes and courtiers.

Unwarranted intrusion of government in scientific methodology and the Mbeki travesties

I do not suggest that there is no role for the government in science. That would be absurd. The government and state contribute in numerous ways to the scientific endeavour, but this is well documented and beyond the scope of this contribution.

It is when the government crosses a boundary beyond its mandate, and often outside its competence, that
serious problems arise. We have, in the Mbeki period, the perfect example. The more egregious actions of this period were presaged by the following: I had chaired a widely representative government-appointed AIDS Advisory Committee in mid-1990s. The carefully derived recommendations of this committee were completely ignored. In a discussion between me and state personnel (who reflected the Mbeki views on ARVs) on prevention of mother-to-child transmission of HIV, which could decrease infant mortality, a government spokesperson calmly declared “…there was nothing to suggest that in impoverished rural areas, saving the life of a child would affect mortality statistics later on.”

The Ministry of Health had supported a very generously funded, aesthetically weak and educationally ineffective play called Sarafina that promised on World AIDS Day, 1995. My professional colleagues and I saw the play and walked out in disgust halfway through the agonising discussion of cause and effect in any biological phenomenon led him to arrange a debate between “denialists” – with little rationality in their arguments against HIV as a cause of AIDS – and the rest of us “conventional scientists”. We were unable to find the words to initiate a rational discussion. It was hopeless.

The 13th IAS Conference
It was in this atmosphere – of the science world’s unmitigated hostility towards Mbeki, his Minister of Health, the late Manto Tshabalala-Msimang, and various segments of the South African – that IAS 2000 took place.

When Doctor David Ho, an American HIV/AIDS researcher who has made pioneering contributions to the understanding and treatment of HIV infection, gave the first presentation and said that HIV was the cause of AIDS, he received a thunderous ovation. In the event, IAS 2000 was a gratifying and unprecedented success in the short history of the AIDS Conferences.

The huge cost of ARVs was contested. The restrictions in global trade, which through the World Trade Organization (WTO) prevented free access to drugs, and the role of the WTO in promoting the exclusivity of intellectual property rights, became legitimate targets of criticism. The Indian Pharmaceutical Company Cipla made the first offer to make generic ARVs affordable. The subsequent fall in the cost of ARVs is shown by the following: the price of three commonly used first-line ARVs for adults fell from $588 a month in 2000 to $51 a month over five years. Within two years of the conference, the number of people on ARVs for treatment had increased from 0.4 million to one million.

A major achievement of the conference then was that the voices of scientists and others from all over the world, supporting the scientific foundations of the cause of AIDS, were heard. The Durban Declaration has an organising committee of over 250 members from over 50 countries. The Declaration was published in Nature (Volume 406, 6 July 2000, www.nature.com), it had been signed by over 5,000 people, including Nobel prize winners, directors of leading research institutions, scientific academies and medical societies, notably the US National Academy of Sciences, the US Institute of Medicine, the Max Planck Institute, the European Molecular Biology Organisation, the Pasteur Institute in Paris, the Royal Society of London, the AIDS Society of India and the National Institute of Virology in South Africa. The following is the concluding quote from the Nature publication: “Science will one day triumph over AIDS, just as it did over smallpox. Cutting the spread of HIV will be the first step. Until then, reason, solidarity, political will and courage must be our partners.”

The impact on democracy
The worrying impact on democracy of this episode is more than conjecture. The unmeasured pervasiveness of unscientific beliefs – including by the president of the country, his cabinet and Parliament – compromised the trust and belief so necessary in an inequitable political system based on regular and unfurling engagement between the ruler and ruled. The essential fabric and character of democracy was contaminated, disgraced and confined as a period.

It may therefore be too far fetched to suggest that the warped reactions by President Jacob Zuma, his Cabinet, the Speaker of Parliament and Parliament itself to the Constitutional Court ruling on the Nkandla case and the impending of the President, are the lasting consequences of Mbeki’s misguided stance on HIV/AIDS.  

Professor Peter Piot
With over 3,000 people dying from HIV infection every single day and 5,500 becoming newly infected, AIDS is not over by any means.

It is not over for the over 20 million people living with HIV who are not benefitting from antiretroviral therapy, and it is not over for all those who are stigmatised and discriminated against because they are living with HIV or are at high risk or vulnerable to HIV. While it is important to celebrate some remarkable achievements and the lives of so many who were saved, it is urgent to take a cold and hard look at the massive old and new obstacles the AIDS response faces and how to overcome them. Not doing so may put the lives of entire generations at risk, and undo hard won gains.

The staggering new infection rates in young women in Southern Africa represent a shameful collective failure despite an increasing armamentarium of prevention methods, as are the continuing HIV epidemics in gay men, sex workers and injecting drug users. HIV prevention has all but disappeared from the AIDS agenda in too many societies and among too many funders. It is an illusion that we will treat ourselves out of this pandemic, even if treatment efforts clearly have to increase and are having a positive impact on the epidemic. We must absolutely embrace and fund combination prevention tailored to the needs of specific communities. The dwindling support for community and activist groups puts the entire AIDS response at risk in many countries and undermines its sustainability. Dedicated funding must continue. Where are human rights in the AIDS response when in so many countries people with HIV are denied access to ART, are still rejected and homosexual is still illegal? The response must be grounded in both science and human rights to be effective and sustainable.

Innovation in terms of treatment and prevention tools has greatly supported the AIDS response. We now also need true innovation in the delivery of HIV prevention and treatment programmes, health system strengthening, community action and the prevention of stock outs. Political leadership on AIDS is at risk if the owners of societies is stagnant. This is understandable as it is very hard to keep any issue on the agenda for decades, which is what is required to defeat AIDS. Now is the time to reinstate leadership and activism on AIDS, build new coalitions, and ensure long-term funding. The replenishment of The Global Fund this year must be a success as any decline in funding will have disastrous consequences.

Political leadership on AIDS is at risk and funding in many countries is stagnant.
So many successes, but too many new HIV-infections

Dr Fareed Abdullah & Kanya Ndaki

As the global HIV community returns to South Africa for the International AIDS Conference, there is no better time to take stock of the progress the country has made.

South Africa is doing remarkably well in the provision of antiretroviral treatment. Of the estimated 6.8 million people who have contracted HIV, almost half (3.2 million) are receiving treatment. This makes us the country with the largest number of people on ART in the world. To put this in some sort of global perspective, our programme contributes no less than 20 percent of the 15.8 million people on ART throughout the world. This achievement is due to the unfailing commitment of the Treasury to fund such a rapid rollout and the unique brand of leadership of our Minister of Health, Dr Aaron Motsoaledi.

Are there problems with the implementation of the programme? Of course there are. Drug stock outs, long queues, low staff morale, poor record keeping – all are to be expected in such a large scale programme and, though government is aware of many of the problems, it remains critical for civil society organisations to point out weaknesses and for government to respond to criticism.

All of the problems and even the difficulties within the public sector about carefully tracking each patient (weak patient management systems) do not take away from the staggering progress that the treatment rollout has heralded. Life expectancy in South Africa has increased from 53 years in 2006 to 61 years in 2012 and mortality has declined by about 50% over a similar period of time. Government spends billions of rand on treatment and the investment is certainly paying off. Few other economic or safety net interventions yield the population level impact seen through this single intervention. The latest UNAIDS report estimates that South Africa has averted 1.3 million deaths through its ART intervention over the last decade.

The success of our treatment programme, however, brings us to a new crossroad in the epic war against the HIV-virus. A successful treatment programme means more South Africans will survive and live longer with HIV. Yet it also means that we are seeing an ever-burgeoning epidemic of HIV as a result of better survival on treatment and a continuing feed of new HIV infections annually.

We estimate there were 330 000 new infections in South Africa in 2014. Using a slightly different methodology, we estimated that there were 469 000 new infections in 2012. The numbers of people living with HIV goes higher and higher. In 2008, it was 5.2 million. In 2012, 6.4 million. Our latest estimates are that we now have 6.8 million people living with HIV in South Africa.

This growing epidemic is unsustainable in the long term from many points of view. Financially, the ever increasing provision of life-long ART to increasing numbers of patients will eventually reach a ceiling, at which point competition with other needs in the health services will limit the growth of expenditure on the ART programme. The health system’s capacity is already stretched to the limit and there will be consequences of an ever-increasing HIV population. At the individual level, with longevity and lifespan treatment there will be missteps in the management of HIV disease that will be cumulative with age and with chronic medication. This all means that we have to seriously turn our attention to prevention.

We have to drastically reduce the number of new infections in the short to medium term. There are two schools of thought on how to approach prevention.

The first takes the view that prevention can be best achieved by a pill as an HIV-positive individual who is virally suppressed on antiretroviral treatment has such a reduced level of infectiosity that the risk of transmission to an HIV-negative sexual partner declines by more than 90%. This view is the option of a negative individual who can take a daily pill and reduce his or her risk of infection from sex with an HIV-positive individual in more than 60 percent of the time and you already have the core of an effective prevention programme through the provision of treatment.

This is a neat argument and there is modelling work that gives it credibility. The models show that, over time, these ‘treatment’ interventions also have a substantial ‘prevention’ benefit. The second view is that no amount of pill-popping, gel insertion or foreskin snipping is going to yield the desired result of a rapid reduction in new infections. There are greater forces driving new infections and these have to do with social and economic factors that define sexual relations in South Africa. There is a so-called ‘political economy’ of HIV transmission that must be understood before its power is to be broken so that the chain of transmission can be similarly unravelled. What is it that drives the cycle of men having liaisons with young women five to 10 years their junior? What are the social and economic dynamics of transactional sex? What are the gender dynamics that make men in life partnerships take on these other liaisons? How much of it is coercion and how powerless is a young woman who is poor, has lost one of her parents to HIV and has just dropped out of school? Is the breakdown of the family in South Africa as a consequence of a 150 years of circular migration so much worse than other countries in the region to account for the extreme rates of our epidemic?

The holders of this second view are quick to point out that this is not one of those deterministic outlooks that end with a fatalistic ‘nothing will change unless the underlying conditions are removed’ point of view. In fact, the social science research is exciting. We know, for instance, that girls in families that receive child support grants are less likely to become infected with HIV, as are girls who stay in school to the full term. We also know that women who experience gender violence are three times more likely to be infected with HIV than those who don’t share this horrible experience. Pregnancy at a young age, we know, puts a young woman in South Africa on the road to HIV.

Consistent condom use is still the single most effective intervention for the prevention of HIV and it would be fair to say that we have not achieved sufficient consistent condom use to see its full benefits. Now that the South African government has the largest condom procurement and distribution programme in the world at least the commodities exist to get men to put them on their penises. We also know that medical interventions often fail because of human behaviour. Men with HIV are not seeking treatment although it is universally available (this would help them and their uninfected partners) and we know that men and women struggle to adhere to both prevention and treatment interventions. This is so severe a problem that the famed Tenofriv get trial failed not because the preparation was not efficacious but because the women in the trial did not adhere to it.

As a country we need to knock heads to bring these apparently differing perspectives together and to find the magic mix of prevention and treatment interventions to break down the constant stream of new infections that puts a more thorough going control of the epidemic just out of our reach. Over the next fifteen to twenty years we have to live in a country where the egregious social, economic and cultural factors that drive HIV are no longer commonplace and where the very promising new prevention tools can realise their full potential – not least of these the HIV vaccine. That is the task facing the South African National AIDS Council and its constituents in government, civil society and the private sector. The conference comes back to Durban after 16 years. AIDS2000 is remembered as the conference that called for the provision of ART to all countries – especially in Africa. Let’s make AIDS2016 the conference that will be remembered for its call to comprehensively tackles prevention.

KANYA NDAKI is the CEO of the South African National AIDS Council (SANAC).

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A time of dying in Durban

Kerry Cullinan

Every day, I passed three funeral parlours on my 5km drive to work in central Durban. Shiny hearses lined up in the street, one behind the other. Fetching, taking, waiting.

When I moved to the city in 2001, death was everywhere. The city’s streets were filled with women wearing black and men with pieces of black cloth pinned to their sleeves. In the rabbit warren of inner city offices, a proliferation of quacks offered expensive “immune boosters”. HIV was too raw and too stigmatised to mention, but the red ribbon accompanying their advertisements made it clear who their treatments were aimed at.

Over the years, I saw many elderly parents escorting their skeletal adult children into these offices, searching for something that would arrest their children’s rapid weight loss, diarrhoea, skin cancer, dementia and other AIDS symptoms. By 2002, St Mary’s Hospital in Mariannhill outside Durban, was having a problem of abandoned bodies, according to the hospital’s superintendent, Dr Douglas Ross. Families were so overwhelmed by funeral costs that they were prepared to risk ancestor wrath, leaving their relative’s bodies unclaimed in the hospital morgue.

Before 1997, every day at the 1 300-bed facility – a staggering 450 deaths a month. Every day, around 240 outpatients came to the hospital with HIV-related problems. HIV was overwhelming the staff and hospital resources. Later, the Medical Research Council found that reported deaths had increased by 57% between 1997 and 2002, while deaths amongst those aged 25 to 49 years had increased by 76%.

Despite Cabinet approval of a comprehensive AIDS treatment plan that would offer free ARVs in all districts of the country in November 2003, years of foot-dragging followed. Health Minister Manto Tshabalala-Msimang, encouraged by President Thabo Mbeki, did her best to elevate various herbal treatments and diets to the same level as ARVs, while Mbeki stressed the toxic side effects of ARVs.

As a series of improper relationships between politicians and business people offering dubious HIV treatments started to flourish, patients’ health was compromised. Tshabalala-Msimang developed a close relationship with Tine van der Maas, who claimed that her diet – olive oil and a supplement called “Africa’s Solution” – was an AIDS cure. Tshabalala-Msimang invited Van der Maas to address all MECs, and introduced her to a number of influential people. In a foretelling of the state capture South Africa is experiencing today, the country’s health department was “captured” by AIDS denialists and quacks at the invitation of the health minister.

At King Edward V Hospital, about 15 people died every day at the 1 300-bed facility – a staggering 450 deaths a month. Every day, around 240 outpatients came to the hospital with HIV-related problems. HIV was overwhelming the staff and hospital resources. Without understanding the irony, Tshabalala-Msimang screened a film shot at Kwakhulelo outside Durban that promoted Van der Maas’ diet at a meeting to promote the launch of the country’s ethical guidelines for scientific research.

In nearby Pinetown, a taciturn former truck driver called Zebulon Gwala made a fortune selling a concoction called ubhejane, a bitter, smoky tasting liquid that was sold in unlabelled two litre milk containers. One of Gwala’s business partners was Dr Herbert Vilakazi, special adviser to the KwaZulu-Natal premier at the time, Sbu Ndebele. Peggy Nkonyeni, then Health MEC, openly promoted ubhejane, while Durban mayor Obi Mbadu sponsored its supply to a hospice in Inchanga.

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**COMMENTARY: AIDS 2000 – AIDS 2016**

We need, along with renewed political will to remedy the current AIDS malaise, to [...] ensure that sustained and predictable financing is in place to support the expanding number of people living with HIV on antiretroviral therapy from 15 million to 37 million.

The ‘end of AIDS’ will not materialise when adult consensual same-sex relations are still a crime in at least 76 countries, including in almost all of the countries where HIV is most prevalent.

...
How the law helps – or hinders – the fight against the AIDS epidemic

Justice Edwin Cameron

It has been almost 35 years since AIDS was identified. Thirty-five long years, since the disquieting realisation that young men in North America, in the prime of their lives, were dying from a hitherto unknown virus. Over 30 million people have died of AIDS, and Africa has borne by far the heaviest burden of these deaths. That figure leaves us numb. It’s hard to imagine each life, each family, each individual physiology of suffering, and decline and death and bereavement.

They have been long and grief-stricken years, but also years of significant successes – gains hard fought-for, which we must consolidate now, if we are to deal successfully with AIDS.

Across the world, about 36.7 million people are living with HIV now. Of these, around 19.7 million people need treatment, but are not getting it. That means that today a disease that, with current medications, is easily manageable is instead sapping the lives and energies and wellbeing of over 19 million people. HIV does not do its devastating work in isolation. It goes hand in hand with tuberculosis (TB) – and, increasingly, with heart disease and diabetes. We also know that the healthcare services in many countries are desperately lacking. The challenges for governments are huge. To provide quality healthcare for all requires dealing with complex obstacles that are not easily overcome. But they must be overcome.

The Office of the United Nations High Commissioner for Human Rights has released an important report entitled The Right to Health. It declares unequivocally that “No State can justify a failure to respect its obligations because of a lack of resources. States must guarantee the right to health to the maximum of their available resources, even if these are tight ... All States must move towards meeting their obligations to respect, protect, fulfil.”

When an epidemic like HIV strikes, governments have a responsibility to respond to the best of their abilities. Equally important, they are obliged to respond according to the best available evidence. With some notable exceptions – particularly the nightmare of AIDS denialism in our own country, South Africa – humanity’s response to the AIDS epidemic has been exceptional. It has shown what can be done when committed healthcare workers, researchers, diplomats, and government officials work with single-minded dedication and focus.

First, medical researchers developed life-saving new treatments. Then, activists campaigned for those treatments to be made available as urgently as possible to the lives that critically needed them. And they fought for them to be affordable, so that everyone – not only the rich – could get treatment.

Millions of lives have been saved, and unspeakable suffering avoided, because of this brave work. And patients’ rights, citizen activism and democracy have been strengthened in the process. To all of this, the law has been indispensable.

In South Africa, it was because we had a Constitution that allows activists to gather, speak out, organise, protest, engage with a free media, and campaign against governmental
obfuscation and delay in making treatment available. And because we had judges of integrity, applying a sound Constitution, government was ordered in 2002 to start making ARV treatment available. It started with pregnant women living with HIV.

Within two years, government had done what it should have years earlier: it promised South Africans they would get what the activists had demanded – a national treatment program.

Today, because of the Constitution, the rule of law, brave, principled activists, and straight-backed judges, South Africa has the world’s largest publicly provided ARV treatment program. More than three million South Africans, like myself, are on ARV treatment. And its boundaries are constantly expanding. Recently, Health Minister Aaron Motsoaledi announced that everyone with HIV, regardless of CD4 count, would receive ARVs.

Elsewhere in Africa, the law, constitutional rights and judges who take them seriously have also had an impact. Just a few months ago the High Court in Kenya ruled against the forced incarceration of two TB patients.

The report amply embraces the gold standard of physical and mental health. It offers a roadmap to ensure that no country’s legal system – has the right to health is the right to the enjoyment of the highest attainable standard of physical and mental health. There are and can be no exceptions.

It explains that “Equality and non-discrimination, inviolable in every key international human rights agreement, are the pillars on which all other human rights rest. So, although there is no binding international law expressly prohibiting discrimination on the basis of HIV status, those two principles guide and support the denunciation of discrimination related to HIV status and against the people it affects.”

A central feature of the Global Commission’s report is its strictures against the damaging, retrograde use of the law to criminalise HIV.

Laws that target people with, or at risk of, HIV are deeply wrong, and deeply bad. They fly in the face of elementary principles of human rights.

The report embraces the gold plate principle of HIV and human rights: that it is both wrong, and counterproductive, to single out people with or at risk of HIV for punitive measures. Measures that violate rights and increase the spread of HIV.

“The criminal justice system,” the report points out, “fights the health care system—one repelling, the other reaching out to people vulnerable to or affected by HIV. By dividing populations into the sick and the healthy or the guilty and the innocent, criminalisation denies the complex social nature of epidemics and fractures the shared sense of moral responsibility that is crucial to fighting the epidemic.”

The lesson is plain. We cannot minimise the impact of AIDS on our societies in a legal environment that disrespects human rights.

Evidence. Evidence. The lawyer’s building block. And evidence is too often disregarded in the epidemic.

Discriminatory laws or actions against vulnerable populations have retrograde effects. Vulnerable communities include people who inject drugs, sex workers, men who have sex with men (MSM), transgender persons, and prisoners. Their rights to human dignity and equality should be embraced.

The Global Commission powerfully recommended inclusive approaches to gender diversity. It urged that “Countries must reform their approach towards sexual diversity. Rather than punishing consenting adults involved in same-sex activity, countries must offer such people access to effective HIV and health services and commodities.”

Similar recommendations were made for other so-called key populations.

Justice and human dignity align strongly with our vision of ending death, discrimination and suffering in the AIDS epidemic.

The commission’s recommendations were published more than four years ago. It’s disappointing that more governments haven’t implemented its insightful, evidence-based recommendations.

Regardless of sexual orientation, job status, or HIV status, everyone has the right to health. If we do not take this right seriously, we will struggle to bring an end to HIV, TB and all the other epidemics threatening our communities.

By doing the right thing, by abolishing discriminatory, harsh, stigmatising laws, and by enacting protective laws, we do also the best thing to reduce the impact of the epidemic. As lawyers and policy-makers, we should know to be guided by the evidence.

JUSTICE EDWIN CAMERON is a judge at the Constitutional Court of South Africa.

The HIV and the Law Commission report can be found at http://hivlawcommission.org/index.php/report

Justice and human dignity align strongly with our vision of ending death, discrimination and suffering in the AIDS epidemic.
Motsoaledi and the devil’s alternative

Ntsiki Mpulo

Health minister Dr Aaron Motsoaledi sat down with Spotlight in an exclusive interview. He shares details on how the department plans to target vulnerable groups in efforts to stem the incidence of HIV. He speaks passionately on plans to target adolescents, a little less forceful on decriminalizing sex work and is thin on detail when it comes to men who have sex with men.

The Health Department’s plan to decrease the HIV-infection rates in adolescents aims to challenge the taboos surrounding sex and HIV, says South African Minister of Health, Aaron Motsoaledi.

In an interview with Spotlight ahead of the International AIDS Conference in Durban in July this year, the Minister outlined a wide-ranging programme for dealing with the groups most vulnerable to contracting HIV in South Africa, with a particular focus on adolescents.

“We have turned a corner on HIV and there are signs that a vaccine is imminent but, according to World Health Organisation research, we still face 5 000 new HIV infections in adolescents per week in Sub-Saharan African and half of those are in South Africa,” says Motsoaledi.

Following the dark period of AIDS denialism, which resulted in the deaths of at least 330 000 people whose lives could have been saved with ARV treatment, the South African government implemented a number of significant programmes that have yielded good results.

“We started an HIV Counselling and Testing programme (HCT) in 2010 and within 18 months had raised the number of facilities offering HCT from 40 to 3 500,” says Motsoaledi.

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Adolescents

According to the Minister, the R3-billion programme, which will span three-years, is aimed at reducing infection rates, bringing down teenage pregnancy and abortions rates, and addressing gender-based violence. This is in addition to keep girls in school and linking them to economic opportunities.

“We have prevalence statistics from each municipality and...”

“We have turned a corner on HIV and there are signs that a vaccine is imminent but, according to World Health Organisation research, we still face 5 000 new HIV infections in adolescents per week in Sub-Saharan African and half of those are in South Africa.”

“Over 3.5 million people are now on antiretroviral therapy and we continue to expand the programme,” he said. “We have now turned our focus to vulnerable groups such as sex workers, men who have sex with men (MSM) and adolescents.”

“We have prevalence statistics from each municipality and...”

“The Minister says the programme will drill down to individual school level and allow the department to profile high-risk schools, with specific programmes tailored to the requirements of that school. “We have prevalence statistics from each municipality and...”

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Spotlight South Africa: Exclusive Interview

Each district in the country based on the antenatal survey, so we have been able to identify the hardest-hit districts,” says Motsoaledi. “Where we find high prevalence, we will immediately put them on ARVs in line with our test and treat programme. “They will receive HIV counselling and testing and, meantime, we will continue to monitor and counsel them to limit the possibility of contracting HIV, and even administering pre-exposure prophylaxis if necessary.”

Responding to criticism that the programme places an unfair burden on girls, Motsoaledi says: “We will not only focus on girls but on men as well. Of the 18 million South Africans on our HCT programme, 65 percent are women, five percent adolescent, and only 30 percent are men. We are insisting that men know their status and we are promoting male circumcision.”

He said the media has paid too much attention on the part of the programme dealing with encouraging girls to stay away from so-called “sugar daddies” who have encouraged some of the programme depended on support from parents and the community. “Parents tell me not to worry about consulting them about screening, immunisation and alcohol and drug education but with respect to reproductive and HCT, they do not even want to engage,” he says. “They say if you give children condoms, you’re asking them to have sex. But the fact that girls are falling pregnant and contracting STIs as a result of some poor policy choices.”

The programme collapsed in 2011 when he visited Umkhanyakude district in KwaZulu-Natal, which is reported to have a high HIV prevalence among young women. “Women came into the clinics asking for contraception and there was none,” he says. “We just didn’t provide contraception in the public health system at the time. It was the result of some poor policy choices.”

According to the Minister, literacy about contraception somehow fell off the agenda at one point in the 1990s. “In our panic to address the alarming rates of HIV infection, we abandoned education programmes around contraception and focused our energies on the ABC programme and, as a result, the contraception programme collapsed.”

But this has changed with the introduction of the dual-protection programme in 2014. This programme has the success of two contraceptive methods, one that protects them from sexually transmitted diseases and HIV as well as from pregnancy. Since then, the department has provided about 800 000 women with sub-dermal implants.

Decriminalising sex work

In addition to the programme for adolescents, the Minister outlined the National Sex Work Sector Plan announced by Deputy President Cyril Ramaphosa, in his capacity as chair of the South African National AIDS Council (SANAC), in March 2016.

In his speech, Ramaphosa said South Africa was one of the first countries in the world to take a decision to provide pre-exposure prophylaxis to sex workers. In addition, government will roll out its test and treat programme in which anyone who tests positive for HIV will be offered treatment regardless of the CD4 count.

Beyond providing health services, the plan for sex workers is expected to address the difficult issues of violence, stigma, alcohol and drug abuse, depression, social isolation, forced migration and lack of economic opportunities.

Responding to the question of decriminalising sex work, Motsoaledi said it is not something that he as health minister can tackle alone. It has implications for the whole of society and must be tackled by the different stakeholders together. To this end, the Minister has consulted with organisations that represent sex workers, including JWEAT, to understand the challenges faced by this sector.

One of the major issues they highlighted was harassment by police officers, says Motsoaledi. “They said police confiscated their condoms thus putting them at great risk for HIV infection. This is something we are addressing with the South African Police Service. Some things can be achieved without having to decriminalise sex work.”

On programmes addressing men having sex with men (MSM), the Minister says there is a need to fully interrogate the issues before plans are rolled out.

“Decriminalising sex work is one of the most direct lines of healthcare. “In the NHI whitepaper we said nurses and community health workers are at the heart of the system, not just about serving, it’s also about selection. We don’t want a primary healthcare worker who will walk into a house and talk about HIV but can’t offer other services or advice,” says Motsoaledi. “When asked about diabetes or high blood pressure they can’t help. We need our community and health workers to be able to help on all levels of primary healthcare.”

He says that his programme already trained some 10 000 CHWs and cited SukhumaSakhe, a service delivery model piloted by the KwaZuluNatal premier’s office through which CHWs were employed, as an example which has been replicated across respective programs.

He suggests that the programme has already borne significant benefits for the province. “When the programme was introduced in 2011, KwaZulu-Natal had the highest prevalence of mother to child transmission, now the province has the lowest.”

The SukhumaSakhe programme was conceptualised to comprise representatives from various departments in the municipalities which would gather information about the state of service delivery in the province through meeting with community representatives on a regular basis. A “war room” to which CHWs and other community representatives could report issues was set up - this was to include health issues like drug stock-outs. A “war room” to which CHWs and other community representatives could report issues was set up - this was to include health issues like drug stock-outs. A “war room” to which CHWs and other community representatives could report issues was set up - this was to include health issues like drug stock-outs. A “war room” to which CHWs and other community representatives could report issues was set up - this was to include health issues like drug stock-outs. A “war room” to which CHWs and other community representatives could report issues was set up - this was to include health issues like drug stock-outs. A “war room” to which CHWs and other community representatives could report issues was set up - this was to include health issues like drug stock-outs. A “war room” to which CHWs and other community representatives could report issues was set up - this was to include health issues like drug stock-outs. A “war room” to which CHWs and other community representatives could report issues was set up - this was to include health issues like drug stock-outs. A “war room” to which CHWs and other community representatives could report issues was set up - this was to include health issues like drug stock-outs. A “war room” to which CHWs and other community representatives could report issues was set up - this was to include health issues like drug stock-outs.

In the much lauded Brazilian primary healthcare programme community health workers (CHWs) are engaged from the local community, are expected to provide contraception in the public health service and support the work of the programme. In addition, government provides pre-exposure prophylaxis to sex workers, and the Department of Health in May 2016, demanding that the Minister address their grievances. In the Free State, 94 CHWs were found guilty of committing the Gatherings Act. They had gathered to hold a peaceful night vigil outside the MEC for Health’s office in 2016 after he had summarily dismissed 100 of them without warning.

In an interview with Spotlight, South African Health Minister Dr Aaron Motsoaledi acknowledged the need for CHWs but said that there was an oversupply of workers who may not have the skills needed to serve the community and public needs.

“Some CHWs require sufficient training in order to discharge their duty to the communities they serve. “The work of primary healthcare is not just about volunteering, it’s also about selection. We don’t want a primary healthcare worker who will walk into a house and talk about HIV but can’t offer other services or advice,”

The minister explains that many nurses and community health workers are often at loggerheads, “Nurses don’t see CHWs as part of the system because of the sporadic nature of their interactions. They see them as nuisances.”

However the Minister sees the issue as one of the most direct lines of healthcare. “The SukhumaSakhe programme will not be a blanket one, which is what they are asking for. If we want to destroy the primary healthcare system, well, just close our eyes and put people into it because they are there rather than assessing the needs of the community and ensuring they have the appropriate skills”, says Motsoaledi.
South Africa and specifically the province of KwaZulu-Natal remains at the epicentre of the HIV epidemic. KwaZulu-Natal has some good stories to tell, but there is still much that needs to be fixed. Spotlight travels the back roads of the province of a thousand hills and finds a buckling lay counsellor programme, quacks and charlatans who prey on people desperate to find a cure and deadly malnutrition in a country of plenty.

| SPOTLIGHT: KWAZULU-NATAL HEALTH |

The next International AIDS Conference needs to be “an earthquake”

Nomatter Ndebele

Ten years ago, the International AIDS Conference was held in Durban in KwaZulu-Natal. Nkosi Johnson, who died a year later at the age of 12 – the longest-surviving HIV-positive born child at the time – addressed the plenary and made a plea to the government to make antiretroviral treatment available to pregnant women with HIV.

At the time, former President Thabo Mbeki pressed on with a campaign of denialism, claiming that there was no such things as AIDS. Thousands of people lost their lives because they were not given life-saving medication. In July this year, the International AIDS Conference heads back to Durban. Thankfully it is a different time.

Today, KwaZulu-Natal has the biggest antiretroviral programme in the country. Of the 1.8 million people diagnosed to HIV, 1.1 million have access to life-saving drugs. Once one of the worst provinces of South Africa in terms of its response to HIV, KZN has now become the model for a functional response to the pandemic.

The province has become the poster child for tireless work to bring about change. Despite this, poor administrative processes and human resource shortages continue to undermine efforts to bring the HIV/AIDS epidemic to an end. Like the rest of the country, the crisis in the public health care system cannot be ignored.

The Treatment Action Campaign has worked tirelessly, particularly in the province, to try to ensure that the most vulnerable people’s needs are put at the forefront of the HIV/AIDS fight. Despite the great strides they have made, the TAC is still wary of the difficult terrain in which they have to work.

Patrick Mlletshe, deputy chair of the TAC said: “KZN Cannot afford complacency, the war on HIV is far from being over. KZN is not immune to problems that are seen and experienced by other provinces like the shortage of essential medicines, high numbers of patients lost to follow up processes exacerbating the steady growth of defaulters. Therefore we cannot pretend that its business as usual.”

Mark Heywood, executive director of SECTION27, a public interest law centre, says: “There are many tangible manifestations of the crisis that we see every day: HR shortages, drug shortages, dirt, disease, corruption and so on. But my concern is the overall inertia, paralysis, decay, demoralisation and lack of will. It’s on a downward slide in many areas. We see best practices and possibility, we have the resources and knowledge to turn it round, but we lack the conviction to do so.”

Human resources are a major concern for Mlletshe as well, “We understand that without community health care workers (CHCW’s) health care system won’t able to keep up with the number of people on treatment as we move to test and treat. We will see more number of people that will default on treatment, next thing people may die while on treatment. It one thing to be on treatment but also is another to adhere on treatment, right now we want people to adhere on treatment and be-viral supress which is an ultimate goal, otherwise having so many people on treatment will be just meaningless,” he said.

Furthermore, political squabbles within the province also impact negatively on the work done by Civil society. “All these political issues could potentially undo all the work we have done as civil society,” said Mlletshe.

Although KZN has progressed far down the road in its HIV mission, there is still a lot of work to be done and complacency is a real danger. This upcoming conference needs to be more than just a formality. It needs, says Heywood, to be “an earthquake that shakes up the complacency and rhetoric around the HIV response”. It needs to find consensus on the priority areas for sustaining and expanding the AIDS response, and to create a new momentum and belief in the possibility of truly overcoming AIDS.

“In other words,” says Heywood, “a repeat of the 2000 conference, but in a very different context.”

Nomatter Ndebele is a Spotlight journalist
The barefoot soldiers of a public health care system that doesn’t seem to care

Nomatter Ndobele

For the past 17 years, 55-year old Doris Ntuli has worked as a community caregiver (CCG) in the community of Sweetwaters, in Pietermaritzburg, Durban. In that time Ntuli has only received a pay increase of R300 (US$20). Her total monthly income is R1500 (US$95).
That one increase was all she’s ever been given. Other than that she and her colleagues work without support or resources in a hostile environment and one which provides little help to the people of the communities they serve.

In 2001, the KwaZulu-Natal province launched Operation Sukuma Sakhe, a social health care model that offers an integrated approach to both social and health-care services. The model puts one community caregiver (or community health worker, as it is generally known in South Africa) in charge of 60 households in order to oversee their health as well as their socio-economic wellbeing.

Care givers report to a “war room” with representatives from various social development departments including Home Affairs, Agriculture, Human Settlements, Health and Social Development. Here they are expected to report any issues affecting their allocated households to the relevant departments, who are then required to intervene, either by going back to the specific household or sending whatever is needed back with CCG.

What should be a strict and formal process however, hardly ever happens. On some days, department representatives don’t show up, and care givers say that not once have they received responses to cases written up in the report books in their absence.

This is one of the reasons CCGs, who are a vital part of the primary health care system, have lost credibility in the community. They never seem to deliver on their promises.

Seven years ago, for instance, on one of her rounds, Doris came across a quadriplegic blind man, who was living in an outside room and needing for himself. Although his family lived with him, they did very little to take care of the man. Doris told the family that she would report the matter and ensure that a wheelchair was delivered to the man.

“For seven years, I went back and forth to that war room to report the matter,” Doris says. “But I received no help. I eventually stopped going back to the house because I was so ashamed,” says Doris. The man died before any assistance came.

For two years now, Doris has left reports at the war room, detailing a case of an improperly sealed sewerage access point.

“She’s not safe. It’s just a big dark hole and if a child falls into that pit, they will be gone,” says Doris.

To this day, the sewage access point remains open and no one from the war room has responded in any way. Doris admits that she is close to giving up on the matter. Clearly, nobody cares. Although CCGs are employed as an extra hand for the departments of health and social services, they are met with much resistance. Nurses in the local clinics look down on them, viewing them as uneducated and providing very little support for the work they do.

Over the past six years, civil society has pushed for the government to recognise community health workers as legitimate aides of the public health care system, and calling for them to be formally employed and given the support they need to do their jobs.

Simanga Sihlebe, a representative from Smani, an organisation that works closely with CCGs in eThekwini, says that one of the biggest issues CCG face is a lack of resources. They have no travel allowance and are not compensated for any expenses. “They often pay out of pocket to provide patients with money for trips to the hospital or clinic,” said Sihlebe.

CCGs are also forced to work with few or no materials. Often, Doris will start her rounds without any materials. Often, Doris will start her rounds without any materials. “I am supposedly working for the Department, but not once have I seen a representative come and address our issues. For years they have ignored us,” said Doris.

The nurses tell me that they only have enough stock for themselves, and that we haven’t been budgeted for,” said Doris.

“People who clean the streets have a uniform. They have boots, but I walk up and down this community everyday in my sandals until they break,” she adds.

Sihlebe explained that dysfunctional administrative processes have an impact on the work of these community health workers. The renewal of contracts is not a well-managed process and CCGs can wait for up to two months to find out whether their contracts will be renewed.

Despite the fact that CCGs are contracted by the KwaZulu-Natal Department of Health on one- or two-year contracts, they receive no benefits at all.

“If I die tomorrow, these children you see here won’t even have 20c to their name” says Ntuli.

For years, the CCGs in Durban have been promised better opportunities, but very few have materialised. When Doris started, she was told that she could be eligible for nursing training. This hasn’t happened, and in the 17 years that she has worked, only two other CCGs she knows have received training. Doris, and many other CCGs in Durban have tried to have their grievances heard. Their peaceful marches and heartfelt pleas have gone unnoticed.

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At the beginning of May this year CCGs in Soweto decided to take drastic action.

Doris joined a group of CCGs who stopped a shut down at the local clinic. The group arrived early in the morning and locked the gates of the clinic, denying patients and staff access. It was only after this act of civil disobedience, that the CCG were promised a response.

Their drastic action was a means to an end, but she and others knew that it will quite likely further strain relations between themselves and staff at the facility.

“We have never had a good working relationship with the sister at the clinic, and after this, I know things will be even worse. But what could we do?”

In spite of all these problems, Operation Sukuma Sakhe is hailed as one of the best primary care health care approaches and is supposed to act as the model on which all other provinces will base their systems.

There is a lot of work to be done in terms of supporting the people who drive the operation. For many people in far-flung rural areas, CCGs are the only line of connection to the public health care system and to social services.

It is not enough to theoretically empower CCGs without providing necessary resources for them to carry out their work.

Photo: Thom Pierce

A community health worker (CHW) prepares to wash an elderly patient. She uses bread bags to cover her hands as she has no gloves.

“Really, we’ve been promised better opportunities, but very few have materialised. When Doris started, she was told that she could be eligible for nursing training. This hasn’t happened, and in the 17 years that she has worked, only two other CCGs she knows have received training. Doris, and many other CCGs in Durban have tried to have their grievances heard. Their peaceful marches and heartfelt pleas have gone unnoticed.

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Photo: Themba Hadebe
Axing of lay counsellors backfires in KwaZulu-Natal

The number of new HIV-positive patients being put onto antiretroviral treatment in medical facilities supported by Médecins Sans Frontières (MSF) in KwaZulu-Natal has dropped dramatically over 12 months, according to the organisation.

MSF, which works in collaboration with the local department of health in uMlalazi municipality, uThungulu District, attributes the estimated 46% drop to a reduction in facility-based testing for the virus in 2015 and the first quarter of 2016.

A strategic objective outlined in the KwaZulu-Natal Department of Health’s Annual Report 2014/2015 is to increase HIV testing coverage in the province to 60 percent of the 5.54 million people aged between 15 and 49 living there by March 2017.

Furthermore, the United Nations has set a target of 90% of people living with HIV accessing ART by 2020. By 2016 MSF estimated that to see 90% of all people living with HIV aware of their status by 2020 under its 90-90-90 initiative, which is designed to help end the AIDS epidemic in South Africa, “you can’t overstate the importance of good counselling. You need to understand that screening would be useless without proper support. It would just be a number – a number you will have to follow up with and that is the hardest part.”

The Western Cape Department of Health was reviewing the role of lay counsellors, but Shroufi concluded the organisation’s medical coordinator for South Africa, “you can’t overstate the importance of good counselling. You can have the most expensive program in the world but at the end of the day if people are not being tested and patients are not taking their treatment it doesn’t do any good. It’s very important that you have the right people in the right place and that you have someone that understands that screening would be useless without proper support. It would just be a number – a number you will have to follow up with and that is the hardest part.”

When contacted the Western Cape Department of Health declined to comment on questions about the review of its lay counsellor policies and whether it was aware of a reduction in testing in KZN over the past 12 months. The official tasked with responding stated the details of the lay counsellor research were confidential to the province, and the department refused to outline their lay counsellor model, saying it was the custodian of the information being sought. However, SANAC spokesperson Kanya Nkadi maintained that the organisation could not comment on the redeployment of lay counsellors, as it is not involved in provincial health department plans.

The KZN department of health or the Office of the Premier in KZN are the only ones that can comment on this matter,” she said. In relation to giving lay counsellors the option to improve their skill sets, Shroufi said that on the one hand it was great to see people’s career prospects improve, but it seemed to be coming at the expense of dedicated counselling.

“What is unfortunate is that people dedicated to counselling in the clinics, and what the province seems to suggest is that nurses will take up the tasks of the lay counsellor, and it is very difficult in busy clinics to put more on the plate of nurses. In practice, what we see is that when you take away lay counsellors a lot of the activities they perform do not happen. We’ve seen a reduction in testing,” he said.

By the time you know someone is not taking their treatment you may be six to 12 months down the line. There is a time delay basically, and that is why we can’t talk about patients’ adherence to treatment yet,” he maintained.

However, MSF believes a decision taken by the KwaZulu-Natal Department of Health to reduce the number of lay counsellors in its 2014/2015 annual report that its Counselling and Testing Campaign.

Through his department’s HIV testing facilities for the first three months of 2016, compared to 850 for the same period in 2015. The department of health’s testing target for the aforementioned facilities for the first three months of 2016 was 5 514, yet only 2 528 tests (or 46% of their target) were carried out during that time.

The department of health says 37.5% (675 952 people) of the uThungulu District population’s 15 to 49-year-olds in uMlalazi, rather than a decline in the HIV-infection rate locally.

MSF’s report on its study said that “after controlling for clinic-level fixed effects and months, we found that having a qualified counsellor is associated with 28 fewer tests per month.”

MSF believes a decision taken by the department in recent years to redeploy its cadre of lay counsellors to training and improved work opportunities, is adversely affecting activities such as HIV testing.

Until the beginning of 2015, KwaZulu-Natal Health MEC Dr Sibongiseni Dhlomo said that counselling and testing had been provided to 2 579 763 people against a target of 58.2 percent.

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When contacted the Western Cape Department of Health was reviewing the role of lay counsellors, but Shroufi concluded the organisation’s medical coordinator for South Africa, “you can’t overstate the importance of good counselling. You can have the most expensive program in the world but at the end of the day if people are not being tested and patients are not taking their treatment it doesn’t do any good.”

This view is also supported by Helen Schneider, the head of the School of Public Health at the University of the Western Cape, who is doing a PhD on community health workers.

“For the first 10 to 15 years in South Africa’s health systems have depended on lay counsellors. They are the gel that has held things together. The United Nations has now put a plan in place (as part of its 90-90-90 treatment targets) to up testing dramatically and lay counsellors are there to do that,” she told the Spotlight.

But a 2013 national department of health circular sent to medical facilities in the province gave forewarning that this important job was to be axed, and that lay counsellors would be retrained and redeployed within the system. It stated that “it has been decided that the lay counselling occupational category should be phased out, which implies that this cadre of employees will no longer be employed by the department with immediate effect.”

The new jobs that lay counsellors can take up after training range from nursing and pharmacy assistant to speech therapist and artisan boiler making. However, the 21 study and retraining needed based on the circular, none were linked to counselling.

Rather than making lay counselling a redundant role in the province, the authorities should be expanding the effect of redeployment on the levels of adherence counselling taking place. “By the time you know someone is not taking their treatment you may be six to 12 months down the line. There is a time delay basically, and that is why we can’t talk about patients’ adherence to treatment yet,” he maintained.

However, MSF believes a decision taken by the department in recent years to redeploy its cadre of lay counsellors to training and improved work opportunities, is adversely affecting activities such as HIV testing.
In KwaZulu-Natal, according to reports from the Human Sciences Research Council, there are 1.8 million people who are HIV positive. Of those, 1.1 million are on the antiretroviral programme. Yet, despite making great strides in the fight against HIV, the streets of KZN are still full of non-medical “healers” who prey on sick, desperate and vulnerable people desperate to be cured of HIV. Nomatter Ndebele visits two “healers” with thriving businesses.

Prayers and pubic hairs

Doctor Sawa’s two-room consultation office is on the 7th floor of an office building in Durban’s CBD. A few blocks from his office, a young woman is handing out pamphlets detailing his expertise, which includes bringing “healers” with thriving businesses. From his office, a young woman is handing out pamphlets detailing his expertise, which includes bringing “healers” with thriving businesses. When the doctor leans forward, I say I am 24 and was diagnosed with HIV three months ago.

"Do you believe in Amakhosi amakhu (the ancestors), sister, and do you thandaza (pray)?"

Because that is what I need to be healed, to pray, and to drink his prescribed muti. The consultation lasts about 45 minutes. Most of it is dedicated to us praying out loud that my ancestors cure me, and while we pray the “doctor” shakes his rattle loudly near my head, and prays out loud that my ancestors cure me. For the first time, I feel truly heard. He says I need to be patient, to come back the following week.

Of conspiracy theories and “healing” juice

Kim Cools has striking blue eyes. Next to his right eye is a puss-filled wound. He tells me to cut down on drinking, “I want nothing to do with that go ahead – we won’t have to use condoms anymore. He also says I never pray, bath, be strong, co-operate, and to drink his prescribed muti. The consultation lasts about 45 minutes. Most of it is dedicated to us praying out loud that my ancestors cure me, and while we pray the “doctor” shakes his rattle loudly near my head, and prays out loud that my ancestors cure me. For the first time, I feel truly heard. He says I need to be patient, to come back the following week.

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There is no such thing as HIV, he later declares. “If I inject myself with HIV-positive blood, how come it doesn’t affect me? It’s simple. If you read the books, there is no HIV,” he says. Even so, he has a cure for this “non-existent thing called HIV”. Cools, is a long-time dissident who has been in the country since 1995. He has spent all of this time trying to awaken the people, he explains. Before Cools came to South Africa, he had been diagnosed with colon cancer and was told he only had four months left to live. It’s 21 years later and Cools sells at least 2 000 bottles a month of the mixture he believes saved his life.

This mixture of ginger, lemon and garlic is now a juice branded “Umlingo” and it is mass produced at a factory in Pinetown, Durban. It is distributed to thousands of people as a cure for HIV, or rather, as a cure for acidic bodies, since there is no such thing as HIV.

"It’s all one big lie,” he says. According to Cools’ website, he is a health practitioner. He is also a conspiracy theorist: there is no HIV, the moon is a hologram, the earth is flat, and there is a giant wall at the end of the South Pole holding vast tracts of land that “they” (The Matrix), are hiding from us. Given half a chance, Cools will tell anyone who will listen about the germ theory, which he has “proven over and over again to be untrue”. The local clinic bear the brunt of Cools’ theories. KwaniGcozi Clinic is a 10 minute drive from Cools’ island plot on Inanda Dam. The head sister there is reluctant to discuss Kim Cools. “I want nothing to do with that man,” she says. “He just keeps confusing the patients with his nonsense.”

In spite of his unsightly eye, Cools is likable. It is easy to see how anyone could get caught up in this friendly man’s theories. There was a time when the patients at KwaniGcozi Clinic stopped coming to get their medication altogether. Given half a chance, Cools will tell anyone who will listen about the germ theory, which he has “proven over and over again to be untrue”. The local clinic bear the brunt of Cools’ theories. KwaniGcozi Clinic is a 10 minute drive from Cools’ island plot on Inanda Dam. The head sister there is reluctant to discuss Kim Cools. “I want nothing to do with that man,” she says. “He just keeps confusing the patients with his nonsense.”

Perhaps the scarcest aspect of his warped self-assurance is his blatant disregard for South African law. He says, repeatedly, that “they are allowing us people to stand up, without doing what Europeans would do, which is put us in prison and shut us up.”

Despite ongoing efforts to rid the province of people like Dr Sawa and Kim Cools, a cycle of poverty continues to drive hundreds of desperate people into the arms of pseudo-scientists and false traditional healers offering any kind of solution to the HIV/AIDS epidemic.
Fewer children are dying of severe malnutrition, but ignorance continues to kill babies

Bill Corcoran & Nolwazi Ndebele

Severe acute malnutrition (SAM) remains stubbornly entrenched in many of KwaZulu-Natal province's rural and peri-urban communities, on-the-ground evidence gathered by the Spotlight suggests.
South Africa has made progress over the past 10 years in reducing SAM levels in young children, according to the 2010 Triennial Report of the Committee on Mortality and Morbidity (CMMMC) in children under five.

From 2009 to 2013 all provinces, except the Free State, were able to reduce the incidence of SAM in the general group of identified malnutrition cases. Indeed, KwaZulu-Natal reduced its prevalence from 8.6 percent to 3.5 percent of recorded cases. However, achieving the national SAM target of just 1 percent of all malnutrition cases remains elusive despite government and international interventions.

The World Health Organisation (WHO) defines SAM by a very low weight for height (below -3z scores of the median WHO growth standards), by visible severe wasting, or by the presence of nutritional oedema.

According to the latest CMMMC report, 26.7 percent of deaths in the under-five age category in KZN had underlying malnutrition in 2013. The province also had the third highest in-hospital mortality rate for SAM in children below five years of age, at 16.4 percent.

Health professionals working at Dundee Provincial Hospital in KZN’s Endumeni Municipality cited poverty, a lack of education, laziness, and the use of quack or fake remedies as the reasons most SAM-affected children had been admitted to their facility.

Hospital records show that in the 15 months to the end of April 2016, the medical facility’s e-ward, where all SAM cases are treated, admitted 59 young children struggling with the condition, of which five died.

“It is unclear how many children with mild-to-moderate levels of SAM attended Dundee Hospital over the same period, as these cases are treated as outpatients, and the information was not accessible to the Spotlight. Lungile Tshabalala, a dietitian at Dundee Provincial Hospital, explained that in many SAM cases she sees, the patients’ mothers do not understand how to nourish their children properly. They try to feed babies with adult food, she said, as they cannot afford baby formula. "This shouldn’t be happening," she said. "There should be people monitoring these kids all the time, rather than just when they are in hospital."

Tshabalala said that nutrition advisors do not always do a good job of advising patients properly because they are under the directive of supervisors who try to impose their own ideas, which are not always best practice.

When speaking to nurses and mothers in Dundee Provincial Hospital’s e-ward, many interviewees said the widespread use of quack remedies and herbal enemas was a contributing factor to the persistence of malnutrition in local communities. "If a child has diarrhoea, the mother thinks the herbal treatment will help," according to Tshabalala. The mothers on ward said that people used such mixtures because they are advised by older generation family members, or traditional healers. One enema that was said to be widely used comprises shoe polish, toothpaste and soap.

Mathias Mabatha, head of traditional health practitioners in the Dundee area, told the Spotlight that children should never be given a health enema, but that "fake" traditional healers often prescribed it for a variety of ailments, including HIV. "The biggest problem is the pseudo-traditional healers," stated Mabatha. "They chop up whatever they can find and just sell it to people on the streets. Sometimes people take enemas without even having them prescribed."

“There is a move to create an official traditional healers forum to ensure that people consult with legitimate traditional healers," he added. It also appeared that many of the mothers who accompanied their children on e-ward were unprepared to deal with motherhood and child rearing.

Nontando Sithole (22), who took her seven-month-old daughter S’inkelwe to see a doctor because she was struggling to breathe, said she had not taken the baby to hospital since she was born because “I was too lazy.”

Mbalai Sithole (19) took her 11-month-old daughter Elitha for an assessment at the hospital on April 29 last year because the little girl had diarrhoea and was vomiting. The child was immediately admitted for SAM. "I thought she was just teething, but she became weak and started to lose weight," said Sithole.

For Umgondwa District where Endumeni is located, the provincial department of health’s annual report for 2014/2015 states that 282 young children were admitted to hospital with SAM for the 12-month-period. In total, 35 of these patients died.

For a province-wide view of the problem, the annual report states that 3 180 cases of SAM in children under five were admitted to hospitals in KZN for the period under review, of which 405 proved to be fatal. In terms of diarrhoea, which in severe cases leads to malnutrition, the number of deaths in the province stands at 30 from 798 cases admitted between 2014 and 2015.

During his April 2016 budget vote speech KZN Health MEC Dr Sibongiseni Dhlomo said that in March 2015 a pilot intervention targeting all households in Zululand District, which has the highest number of malnutrition deaths for children under five in the province, was launched. This was followed by a broader roll out of the initiative across the province.

“The main outcome of the community-based profiling recommended by the model was that children were identified earlier with fewer complications, and thus had better health outcomes. "There has since been a 22% reduction in deaths related to severe acute malnutrition in the province since the last financial year," he stated before adding that “all other districts have been encouraged to roll out implementation of the model so that the province perseveres in achieving optimum child health.”

When the KZN Department of Health was approached to contribute to this article, they failed to address any of the questions submitted to the KZN Health MEC’s spokesperson, despite being given a number of weeks to respond. So, whether its latest intervention is viewed by the department of health as a watershed moment strategically, and has the desired impact of driving down the number of SAM deaths to the 1% national target, remains unclear.

Hospital records show that in the 15 months to the end of April 2016, the medical facility’s e-ward, where all SAM cases are treated, admitted 59 young children struggling with the condition, of which five died.
The good

Good news is that it’s an election year. Road works are everywhere and, irritating as they may be to endure sometimes, they signal investment in much-needed infrastructure. The same can be said of upgrades and refurbishments at some clinics and hospitals. Sections of Pelonomi Regional Hospital look swish and modern and ready for action, and the once dilapidated Batho Clinic on the outskirts of Bloemfontein is undergoing a revamp. More good news has come in the form of ground-up initiatives. Projects like the ARV Adherence Club, managed by MosoMania, have managed to divert 11 000 HIV-positive people out of hospital queues in under two years. This has relieved queue congestion at hospitals and clinics but has also, importantly, introduced better monitoring and tracking to help keep patients from defaulting. Perhaps the best of the good news is an acknowledgment from Premier Ace Magashule, in a meeting this May with the TAC, that civil society structures and government need to meet more often, need to understand one other better, and need to find common ground to heal a broken healthcare system in the province.

The meeting was a public dressing down of Health MEC Benny Malakoane, with Magashule chastising Malakoane for failing for five years to meet with the TAC. The meeting was also a call from government for greater cooperation and less personalisation in the fight for a transformed healthcare system and for the members of his executive committee to do better. This is plain speaking from an official of rank. If his sentiments are true, it is a positive step towards undoing the bad and ugly that’s pervasively pervasive in the province.

The bad

The bad and the ugly in the Free State have been debilitating. The provincial government has steadfastly denied that it rules over a crumbling health-care system, including the failed NHI pilot district of Thabo Mofutsanyana. There has been a lack of transparency, bureaucracy has been used as a device of obfuscation, and there’s been very real intimidation of those who dare challenge Health MEC Benny Malakoane. All of this has only served to deflect from the work that still needs to be done in the Free State and the reality that the real casualties are counted in lives lost.

The ugly

Tyranny is an insidious disease that spreads from top structures to those who mimic Malakoane’s style of leading by intimidation, denial and deflection. It filters down to regional heads who won’t engage and nurses who are rude with impunity. The flip side of tyranny is intimidation and fear. There are those who loathe Malakoane but feel they need to protect their identities because their jobs may be on the line. They speak out only on condition of anonymity. Throughout the province residents, activists, nursing staff and community workers are speaking out more and more about the change that must come. They want a health-systems overhaul that will ensure proper capacity in their facilities, excellent management and respect and dignity for the thousands who rely on public health care in the province. Where hope lies

There must be an end to working in silos for infrastructure needs to not be reduced to hollow buildings filled with equipment that no one ever used. This is true of Pelonomi Hospital and Batho Clinic. True too, of the Trompsburg Hospital, which was scheduled to be opened in October 2014 and is now only scheduled to open in July this year. The build never made budget and there remains a funding deficit to buy equipment and hire staff. It’s only sensible that an integrated approach, one that factors in infrastructure development, proper equipment and maintenance, and staffing. Only a long-term vision can attract and retain staff in the public health sector and grow confidence among those who rely on the services.

Clearly the Free State has not broken free of its chains just yet. Reports still circulate, like the ones from Netwerk24 of no single gynaecologist or any specialist staff to oversee the more than 4 800 births that take place at Pelonomi Hospital. Vacant positions have simply remained unfilled, although the department says there’s been no “hiring freeze”.

There’s also the report by GroundUp of the #HinaAbuse Twitter campaign launched in May this year as desperate, qualified nurses (an estimated 250 of them), cannot get work in the province. There’s also the matter of the still unanswered questions by opposition parties, residents – and even matrons and doctors – over the tender process of Buthelezi Emergency Medical Services in the Free State and about whether they are fit to operate as per their contract. More lingering bad and ugly news is that Malakoane, along with seven other Free State officials, is still to answer to charges of accepting bribes, fraud and corruption. The amount in question is believed to be around the R20-million mark and charges date back to between 2007 and 2009. Malakoane was municipal manager of the Matjhabeng municipality at the time. Malakoane’s punitive and petty management style also means that qualified nurses (an estimated 250 of them), cannot get work in the province.

Activists, meanwhile, will keep up the pressure: residents and locals still need to be heard. They still need to be the central voice in the next chapter of the Free State health services story.
To understand what led to the crises in the Free State it is helpful to backtrack to 2005 when the provincial scale-up of antiretroviral therapy (ART) programmes across South Africa’s nine provinces began in earnest. In the absence of guidelines, norms or standards issued by the National Department of Health, the Free State had developed its own systems for scale-up. The province struggled to backtrack to 2005 when the provincial scale-up of antiretroviral drug, and partly before ARV sites were allowed to laborious accreditation process for many who lived outside the few urban areas. of centrally located clinics meant that treatment remained inaccessible for treatment, and its model of ARV provision through a small number developed its own systems for scale-up. The province struggled to issued by the National Department of Health, the Free State had began in earnest. In the absence of guidelines, norms or standards therapy (ART) programmes across South Africa’s nine provinces of the HIV/AIDS department.

At the time the province had no methodology by which it set treatment targets and aligned these with budgets. At the time, the Free State also had the lowest rates of provincial ARV treatment coverage, at only 25% of those eligible for treatment was accessing it.

3 November 2008

The head of the Free State’s Comprehensive HIV and AIDS Management Programme emailed the provinces Chief ARV Pharmacist with an instruction in the subject line to stop putting new clients on ARVs. The email stated: “This province (Free State) is experiencing an acute shortage of antiretroviral drugs...This will lead to clients on treatment defaulting not because of their own fault. The only way to avoid this is by keeping the remaining ARVs for the exclusive use of those on treatment already with the exception of clients on the PMTCT program (pregnant women). In the meantime the FSDH (Free State Department of Health) will be trying to find ways to remedy this situation”.

The Chief ARV pharmacist forwarded this email to healthcare workers and facility managers, acknowledging its serious implications: “We are facing a difficult period. You at the sites are faced with an even worse situation whereby you have to turn patients away because of the present circumstances. The same patients who look at you as their last hope in life.” The ARV moratorium was the forerunner in a series of cost curtailment measures, which were implemented by all 31 public healthcare facilities in the Free State on 24 November 2008. These reduced the services available by drastic measures, and terminated all outreach services (with the exception of oncology). Clinical admissions were limited to “dire need only”, and at one hospital patients were instructed to “go home and phone to hear if a bed is available”.

Hogan reacted to the Free State’s ARV moratorium, committing additional funds to replenish drug stocks and dispatching health systems experts to the province. The minister arranged for the transfer of R9.5 million in emergency funds to the province to purchase ARVs. The moratorium, which was part of a series of cost curtailment measures, lasted for four months. During this time, an estimated 30 additional patients in the province died from AIDS each day. The moratorium contradicted national government’s commitment to the scaling-up of antiretroviral (ARV) treatment to 80% of those in need by 2011. As the first official cessation of provincial rollout, the moratorium served as a litmus test for government’s reaction to critical challenges in the expansion of the ARV treatment programme at both national and provincial levels. It therefore provides a valuable case study for the state’s response to some of the systematic and health infrastructural problems that have characterised South Africa’s ARV rollout since its inception. It was also the first litmus test for the post-Mbeki government, even thought it was very much as a result of and a legacy of that period. Contributing factors to the Free State ARV moratorium were [Source: Hodes, R., & Grimsrud, A. 2011. The antiretroviral moratorium in the Free State province of South Africa: Contributing factors and implications. Centre for Social Science Research, University of Cape Town, Working Paper No. 201].

27 June 2014

Community health workers gather at Bophelo House in Bloemfontein, the headquarters of the Free State Department of Health. Their contracts had not been renewed and they had not been offered an explanation. A meeting with a health official leads to an agreement that a meeting with Health MEC Benny Malakoane will take place within seven days.

3 July 2014

The Treatment Action Campaign (TAC) releases the results of a fact-finding mission across the province.
It is established that there is a health care moratorium in the province with massive stock-outs, shortages and system collapse. There is a call for the Health MEC to be fired. In addition the TAC make the following demands: Premier Ace Magashule must remove Benny Malakoane from his position as MEC of Health in the Free State. If Magashule is not willing to do this, we call on the ANC's national leadership to intervene. Recently dismissed community healthcare workers must be reinstated with immediate effect. A turn-around plan for the provincial health system must be developed as a matter of urgency. It is essential that this turn-around plan be led by committed and qualified people – and not the current MEC. The secretariat of the Provincial AIDS Council must be moved out of the Department of Health so as to ensure independence and more effective civil society engagement. The Free State Department of Health must come clean about its financial problems. The public has a right to know how the Department is spending money – especially in the midst of a crisis like the current one. The MEC and Cabinet publish a fact-finding report into the health system collapse in the province and makes allegations implicating the MEC in a “ICU bed for pall” scandal. (http://mg.co.za/article/2014-07-03-how-a-dying-women-s-bed-was-taken-by-an-official). 

9 July 2014

Over 100 community health workers (CHWs) and TAC activists from across the province start a peaceful vigil outside Bophelo House to protest against the dismissals of their colleagues. The TAC announce the commencement of a civil disobedience campaign. Reports emerge of MEC Malakoane phoning CHWs, warning them that they will be arrested if they participate in the protest action. He demands the names of those attending the protest. Police presence increases significantly and they start negotiating with CHW and TAC leadership.


10 July 2014

Further police back-up arrive on the scene and protestors are ordered to disperse or face arrest. Police tell protestors they have been sent by the Health MEC Benny Malakoane. Police move in and start arresting male CHWs and male TAC activists. Arrested protestors are taken to various police stations where they are locked up. Protestors are told they are being charged for taking part in an illegal gathering. Later in the day another 50 TAC members are arrested for picking outside Bophelo House and taken to Park Road police station. They are forced inside police vans.

TAC General Secretary Anelè Yawa contacts ANC General Secretary Gwede Mantashe who indicates that he does not see it as his responsibility to deal with the ANC leadership in the Free State. Media statement: http://www.tac.org.za/news/police-arrest-over-100-health-workers-and-activists-stopping-peaceful-vigil-outside-fs-health

11 July 2014

All those arrested appear in court and are told to again appear in court on September 1.

16 July 2014


17 July 2014

About 1000 activists march to Bophelo house, the Free State Department of Health headquarters. The activists demand the immediate dismissal of Free State Health MEC Benny Malakoane, the reinstatement of recently dismissed community health workers on new terms, and a clear action plan to fix the Free State health system. The group also marches to the Provincial AIDS Council to give the council’s secretariat a memorandum to acknowledge the falling provincial health system and call for the MEC’s resignation.


1 August 2014

The case is transferred to Bloemfontein Regional Court and postponed until the 27th of August. A TAC night vigil continues into the morning and 50 TAC comrades picket outside the court.

http://www.cmf.co.za/article-local-news/50572/50572-132080

8 August 2014


11 August 2014

The nurse studies strikes at Bongani Hospital grows into a massive campaign; they stated that no one will be working until their demands are met.

14 August 2014

Free State TAC meets with the public protector. She says they are aware of allegations of corruption against Benny, but her office needs more facts in order to investigate. The new doctor appointed head of the HIV program in FS requested to meet with TAC and wanted to create a platform to have monthly meetings.

19 August 2014

2 organisations attended a TAC partners meeting in Johannesburg on the state of healthcare in Free State.

27 August 2014

MEC Malakoane appeared in the Bloemfontein Magistrate's court on charges of fraud and corruption relating to his time as Matjhabeng Municipal Manager. The case was postponed until November.

4 September 2014

The corruption case transferred to Bethlehem Police Station – case number 219/9/2014. No investigating officer had been assigned due to the absence of a hard copy of the dockets.

2 October 2014

All those arrested appear in court and are told to again appear in court on October 2. TAC brings charges of corruption against Free State MEC for Health Benny Malakoane, Head of Free State Health Department Dr David Motau, Free State Deputy Director General for Health Tebogo Moji and senior officials in the provincial Department of Health at the Park Road police station in Bloemfontein. The charges relate to the matter reported in the Mail & Guardian newspaper on July 20, 2014. The article titled "How a dying women’s bed was taken by an ANC official" states that MEC Malakoane had ordered that an ICU bed for an AIDS patient at DHlabeng Regional hospital should be made available to an ANC official – even though clinical guidelines did not indicate that the official should be given a bed. The Mail & Guardian quotes doctors indicating that other patients would have benefited more from access to the ICU bed. One of these patients died shortly after.


9 November 2014

General for Health Tebogo Moji and senior officials in the provincial Department of Health at the Park Road police station in Bloemfontein. The charges relate to the matter reported in the Mail & Guardian newspaper on July 20, 2014. The article titled "How a dying women’s bed was taken by an ANC official" states that MEC Malakoane had ordered that an ICU bed for an AIDS patient at DHlabeng Regional hospital should be made available to an ANC official – even though clinical guidelines did not indicate that the official should be given a bed. The Mail & Guardian quotes doctors indicating that other patients would have benefited more from access to the ICU bed. One of these patients died shortly after.


27 January 2015

The NDPP responds to the written representations made by the CHWs that the case would not be withdrawn. http://www.tac.org.za/sites/default/files/NDDP%20Response.pdf

29 January 2015

All those arrested appear in Bloemfontein Magistrate's Court for the fourth time. The prosecutor offered a settlement in order to drop the charges with conditions attached. The settlement amounted to an admission of guilt that “the government is aware that what they will not parteake in any "unauthorised" gathering in the future. Failure to comply with this would amount to the charges being reinitated. The admission of guilt was found by the vast majority of CHWs and TAC members to be unacceptable. The settlement was rejected by TAC and accepted by TAC. The TAC were told to re-appear at court on March 30.


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TAC releases a satire newspaper with the headline “Benny Fired – Incompetent Free State Health MEC Dismissed”. Amongst others the newspaper featured an article detailing Premier of Free State, Ace Magashule’s plan to turnaround the crisis in the Free State health system, and a job description for a new MEC of Health in Free State. The newspaper was distributed inside the State of the Nation at Parliament. In addition banners were held stating “ANC fires Free State MEC – Viva!” along the highway.

ANCYL FS, ANCW FS, and SANAC Men’s Sector Free State, march for the de-registration of TAC. Reports suggest 200 people attended. Statements issued by various organisations in support of TAC.


TAC leader Malakoane regarding a political fight and hold the provincial Department of Health accountable.

The report lists several recommendations for the Free State. The report recommends that the findings of the report be investigated by several different agencies and that the Free State Department of Health create a task team which involves community members to deal with these findings. The report also recommends that the Free State Department ensure that there is adequate funding and personnel to update and maintain health facilities and medical supplies. The Free State Department of Health must also address human resource issues including staff shortages, mismanagement, and poor working conditions.

12 May 2016

TAC and others, 500 people total, marched to the Park Road police station and the Free State Prosecuting Authority in Bloemfontein to demand that the charges TAC laid against MEC Makoale not to be delayed any further.
MEC* Malakoane: What the Treatment Action Campaign is charging him with

The charge

The offense of “corrupt activities” in terms of section 6 of the Prevention and Combatting of Corrupt Activities Act 12 of 2004 (“the Act”).

An article titled “How a dying woman’s bed was taken by an ANC official” appeared in the Mail & Guardian on 4 July 2014.

The article states that MEC Malakoane, with the assistance of his Head of Department David Motau and Deputy Director-General Tshabo Moji ordered that a patient be admitted to the Intensive Care Unit (“ICU”) at Dihlabeng Regional Hospital despite that the patient did not qualify for admission to the ICU and patients who did qualify for admission had been turned away the same night because the ICU was at capacity. The article indicates that the officials ordered the patient to be admitted to the ICU due to the patient’s political position and connections. The patient was admitted and several other patients who qualified for admission were turned away while he was occupying a bed. A patient who was removed from the ICU to make room for the undeserving patient died in an ordinary ward of the hospital.

The evidence

On 27 June 2014, MEC Malakoane and HoD Motau entered Pekholong Hospital in Pektahlo to refer a patient (“Patient X”) to Dihlabeng Regional Hospital to be admitted to the Intensive Care Unit. Pekholong District Hospital does not have an ICU whereas Dihlabeng Regional Hospital does.

A doctor who informed the Mail & Guardian of this information requested anonymity for fear of being fired. Moreover, the real name of Patient X is known to the Mail & Guardian.

It is alleged that Patient X was politically connected and an office bearer of the African National Congress. When Patient X arrived at Dihlabeng Regional Hospital, the ICU consultant on duty assessed him and found that he did not qualify for admission to the ICU because he was in the last stages of a chronic condition and was unlikely to recover. A senior doctor at Dihlabeng hospital explained “no other ICU in the country would admit a patient like that, especially over other patients we could more likely save.” The ICU was at capacity and two critical patients had been turned away that night due to space constraints.

Even though a patient with a prognosis like that of Patient X is usually cared for at a primary level, Patient X was admitted to a secondary level medical ward.

The following morning, on Saturday 28 June 2014, MEC Malakoane issued an instruction to the Clinical Manager on duty at Dihlabeng hospital to admit Patient X to the ICU. Deputy Director-General Mr. Mondli Mvambi delivered this instruction on behalf of MEC Malakoane. The Clinical Manager on duty at the ICU said that it was explained to him “the MEC had promised family members the patient would go to ICU.”

Another doctor at Dihlabeng hospital explained that “the medical professionals on duty were in trouble for not sending [Patient X] straight to ICU” even though Patient X had already been admitted to a higher level of care than he should have been.

On 2 July 2014, Patient X remained in the ICU without improvements to his condition. It is alleged that during the previous days, several critical patients deserving of admission to the ICU were turned away due to the lack of capacity. It is particularly alleged that a patient who qualified for admission to the ICU but was turned away died in an ordinary ward of the hospital on Monday 30 June 2014.

In addition to the information reported in the Mail & Guardian, the TAC has reason to believe that Patient X was a relative or associate of another senior political leader in the Free State.

The TAC also have reason to believe that members of the staff at Dihlabeng Regional Hospital and Pekholong District Hospital can confirm the facts reported in the Mail & Guardian.

The MEC’s defence (two conflicting reports)

Version 1

In an interview with eNCA aired at 12:00 on 11 July 2014, MEC Malakoane’s spokesperson, Mr. Mandl Mvambi, asserted that MEC Malakoane went to Pekholong Hospital, saw Patient X and assessed his file. Mr Mvambi explained “the MEC is a doctor in his own right. He saw this patient, he saw the file, he called the clinical specialist in the hospital, assessed the file and jointly agreed with the specialist that this was a deserving case for the ICU.”

Version 2

An article appearing on page 15 of the Mail & Guardian on 22 August quotes MEC Malakoane as providing a very different account: “I didn’t even know the patient’s identity or that he had been transferred to ICU … All I did was to ask [medical personnel] to isolate the patient, who appeared to be in a coma, to prevent psychological trauma to the ones next door.” (“They call me a killer when I know I’m a saviour, says Malakoane”, Mail & Guardian, 22 August 2014).

What the prevention and combating of corrupt activities act says

Section 4 of the Act reads as follows:

4. Offences in respect of corrupt activities relating to public officers (i) Any - (a) public officer who, directly or indirectly, accepts or agrees or offers to accept any gratification from any other person, whether for the benefit of himself or herself or for the benefit of another person; or (b) person who, directly or indirectly, gives or agrees or offers to give any gratification to a public officer, whether for the benefit of that public officer or for the benefit of another person, in order to act, personally or by influencing another person so to act, in a manner— (i) that amounts to the— (aa) illegal, dishonest, unauthorised, incomplete, or biased; or (bb) misuse or selling of information or material acquired in the course of the, exercising or performance of any power, duties or functions arising out of a constitutional, statutory, contractual or any other legal obligation; (ii) that amounts to— (aa) the abuse of a position of authority; (bb) a breach of trust; or (cc) the violation of a legal duty or a set of rules; (iii) designed to achieve an unjustified result; or (iv) that amounts to any other unauthorised or improper inducement to do or not to do anything, is guilty of the offence of corrupt activities relating to public officers.

(2) Without derogating from the generality of section 4(2), “to act” in subsection (1), includes— (a) voting at any meeting of a public body; (b) performing or not adequately performing any official functions; (c) expediting, delaying, hindering or preventing the performance of an official act; (d) aiding, assisting or favouring any particular person in the transaction of any business with a public body; (e) aiding or assisting in procuring or preventing the passing of any vote or the granting of any contract or advantage in favour of any person in relation to the transaction of any business with a public body; (f) showing any favour or disfavour to any person in performing a function as a public officer; (g) diverting, for purposes unrelated to discharging an official duty or a set of rules of any business with a public body; (h) taking any improper influence over the decision making of any person performing functions in a public body.

The TAC believes that the officials may have agreed to accept “gratification” for the benefit of Patient X in the form of a bed in the ICU and the financial and other resources that accompany the bed. In addition, the TAC believes that: • MEC Malakoane may have agreed to accept “gratification” in the form of goodwill and political favour from Patient X and/or his political connections, including another senior political leader in the Free State; • HoD Motau may have agreed to accept the same “gratification” from these sources as well as from MEC Malakoane; and • DDG Moji may have agreed to accept the same “gratification” from these sources as well as from MEC Malakoane and HoD Motau.

* An MEC is a provincial minister.
The relationships between these individuals may constitute a "mutually beneficial symbiosis ... generating a sense of obligation" on the officials; such relationships have been determined to be a form of "gratification" for the purposes of a charge of corruption under section 6(b) of the Act. [S v Shak 2007 (1) SA 240 at 33].

By ordering Patient X to be admitted to the ICU, the TAC believes that the officials may have: 
- abused their position of authority; 
- violated a legal duty and a set of rules; and 
- acted in a manner designed to achieve an unjustified result.

The TAC believes that the officials' act of ordering Patient X's admission may have included: 
- a failure to adequately perform his official functions; 
- showing favour to Patient X and disfavour to other patients in performing a function as a public officer; 
- diverting property belonging to the state to Patient X for purposes unrelated to those for which it was intended; and 
- exercising improper influence over the decision-making process of performing functions in a public body.

What the Constitution says 

The TAC also believes the MEC may have acted in contravention of section 195(1)(b-c) of the Constitution as well as the Executive Ethics Code made in terms of the Executive Members Ethics Act 82 of 1998. These laws specifically prohibit MECs from:
- using their position to enrich themselves; 
- improperly benefiting another person; 
- acting in a way inconsistent with their office; and 
- exposing themselves to a situation involving the risk of a conflict between their official responsibilities and private interests.

What the State is charging with 

The National Prosecuting Authority has charged Malakoane with multiple counts of corruption for which he faces a minimum sentence of 15 years imprisonment. He was arrested in regards to these charges on 10 July 2013 following a 2010 Commission of Enquiry that produced incriminating allegations against him. The prosecution alleges that Malakoane used his position as Municipal Manager of the Malabatheng Local Municipality in 2007 and 2008 to conduct extensive fraud and corruption. 27 August 2014, his prosecution was again postponed for the umpteenth time.

Ufrieda Ho 

Nurses are giving Cecilia Mokole dirty looks. Mokole meets their stares. She doesn't care anymore what they think, or what they may do to her for speaking out. She cares about what it is for their patient. She has her grandchild on her lap, she is right. At 8.15pm she sends an SMS. She's finally been attended to. She's a lot happier that it is for her. She is right. She is right. At 8:15pm she sends an SMS. She's finally been attended to and been given a pain injection, but she has to return the next day for an X-ray to determine whether she has broken her leg. Each trip to and from the hospital costs her R40.

Still, the next morning she's back at the hospital. She has no choice: she has to get the X-ray. She has to get pain tablets. She takes up her seat on the waiting benches. The waiting begins all over again. She really is fed up with this hospital. It's not like a hospital, it's like a clinic. They must hire more people. Now I must sit and wait till the doctor on night duty comes," says Mokole, her leg resting on the bench. The queue of benches is a child on a drip, lying on his mother's lap. Another eight patients are just sitting quietly as sun dips towards the horizon. No one complains, except for Mokole. Even this makes her mad. She's tired that people have to put up with bad service and that everyone is forced to keep silent because of the threat of being treated poorly. She has her granddaughter on her lap, babysitting her, so her grandson can get some food for them because Mokole thinks it will be a long night. Even at 5pm she doesn't believe her wait is over. And she is right. At 8:15pm she sends an SMS. She's finally been attended to and been given a pain injection, but she has to return the next day for an X-ray to determine whether she has broken her leg. Each trip to and from the hospital costs her R40.

Ufrieda Ho is a Journalist

Cecilia Mokole waits for hours in the JS Moroka Hospital for someone to attend to her leg. She had to make three trips before she got the medical help and X-rays that she needed.
Feeling like a beggar for medicine

Ufrieda Ho

Long shadows stretch over a scrap of veld outside the Bhopelong Clinic, just outside Welkom’s city centre. It’s gone 4pm and the clinic has shut its doors for the day.

The nurses have turned away a handful of patients – there just aren’t enough hours in the day to help everyone, they say. Among those turned away are *Anathi and *Eunice, two in their 50s. Both have been in the queue since before the clinic opened its doors at 8am, for their appointment cards. Both have been told to come back the following day to collect their medicines if they need them and both are anxious about whether they’ll actually get their medicines then.

From her bag *Anathi pulls out a container of pills. She has three tablets left of her FDC medicines. She’s been on ARVs since 2008. “I am worried that if I come back tomorrow that the will tell me they can’t help me again,” she says. She adds: “It takes me about twenty minutes from my place to walk to the clinic. But still it’s better for me than it is for *Eunice. I don’t work, I don’t have anywhere to go tomorrow, so I can come back. But *Eunice has to go to work. Work for me feel like I don’t have balance and my knees go weak. My blood is used to having this tablet, but now tomorrow I won’t have this and I have to walk all that way,” she says.

*Eunice adds: “They say tomorrow when I come I can go straight to the front of the queue. But this is not right. Many times the nurses give us problems. Some are good, but some speak to you in bad way even though I know this clinic very well, because my three children all came to this clinic. But you can’t say anything, I can’t speak up because I have nowhere else to go. “This makes me feel very sad, it makes me feel like I must beg to be helped. They make you feel like you are a beggar.”

*Not their real names.

Nurse X has been working in the Free State Health care system since 1988. She’s risen through the ranks over the years and has watched with a heavy heart as the department has slipped into a state of dysfunction – a casualty of gross mismanagement and too much political interference. She has a long list of what’s gone wrong: the provoke of established nurses from public health care; posts being frozen; nurses not being paid overtime for more than three quarters of last year; budgeting that has compromised the efficient running of institutions; private ambulances arriving to fetch patients without surgical gloves and drip kits, but “start charging you the minute they arrive”; intimidation from politicians who allow politicking to go on in hospitals and clinics, but prohibit senior personnel, like herself, to speak to the media.

She doesn’t want her identity revealed because she says the politicians have become tyrants. At the same time they want to share their stories because the service is just not good enough, they say. *Eunice is even more worried than her friend. She took her last blood pressure tablet that morning. She won’t be able to make it back to the clinic the following morning because she has to go to work. Work for *Eunice is cooking at a local school, an hour’s walk from her house. “I don’t know if I will make it when I have to walk back from the school to the clinic tomorrow afternoon.

When I haven’t had my tablet it makes me feel like I don’t have balance and my knees go weak. My blood is used to having this tablet, but now tomorrow I won’t have this and I have to walk all that way,” she says.

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*Not their real names.

Trying to nurse ethically in a broken system

Ufrieda Ho

“I didn’t go to nursing college to become a politician,” says the matron in her next office in the facility she heads up. Nurse X has been working in the Free State Health care system since 1988. She’s risen through the ranks over the years and has watched with a heavy heart as the department has slipped into a state of dysfunction – a casualty of gross mismanagement and too much political interference. She has a long list of what’s gone wrong: the provoke of established nurses from public health care; posts being frozen; nurses not being paid overtime for more than three quarters of last year; budgeting that has compromised the efficient running of institutions; private ambulances arriving to fetch patients without surgical gloves and drip kits, but “start charging you the minute they arrive”; intimidation from politicians who allow politicking to go on in hospitals and clinics, but prohibit senior personnel, like herself, to speak to the media.

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*Not their real names.

Ufrieda Ho

“We cannot go on like this.”

“We cannot go on like this.”

“We cannot go on like this.”
Who will help the sick and needy?

Ufrieda Ho

Back in the mid-90s, Angelina Manale Mookadi had dreams of becoming a nurse. “I thought it was a profession I could afford because the government was going to help me pay for my studies. And I always wanted to help my community,” she says, sitting in the kitchen of her home in Tsephong, outside of Welkom, in the Free State.

She flips through a photo album of her early days working with the community. In the pictures she’s in her 20s and she’s dressed in neat white tops and dark skirts – dressed to visit her patients. She smiles as she looks at photos and talks about former colleagues and “the good ol’ days”.

Mookadi never went on to become a nurse and became a community health worker (CHW) instead. It has never mattered to Mookadi because being of service was and still is what counts for her.

This year marks 20 years of service that Mookadi has under her belt. They’ve been proud years mostly, but the last two years have signalled a turning point that has disappointed her, hurt her even.

In 2014 the Free State Department of Health dismissed around 3 800 community health workers on the grounds of not having a matric or for being too old to do the job. The following year a peaceful candlelight protest at the Free State Health Department’s Bophelo House led to the arrest of over 120 community health workers. Of those, 94 were charged for being part of a “prohibited gathering”. The case is on-going.

“I’m one of the 94 people who still faces charges. It has been painful to have worked for such a long time and to be treated like this by the MEC. I was one of those got my job back because I have a matric, but there are many other CHWs who are going hungry. “We are the people who have the experience and we know what our patients need. They need us so they don’t become defaulters so that they can be healthy again – we are the ones who know what they go through. “Sometimes we bring food and sometimes we even have to help wash them, but that is what we are used to doing and we do it to help them,” she says.

Mookadi says the MEC’s decision to axe the CHWs has already had negative repercussions. It has increased the patient load for the current pool of working CHWs, so that they seldom get to see all the patients on their list in a typical day. Neither do they get paid more for their extra workload – they still receive a stipend of only R1 700. It’s made the job tougher for CHWs who still only receive a R1 700 a month stipend.

Mookadi is committed to adding more years to her service record in spite of these challenges and the court case that is playing itself out slowly. She feels compelled to speak out against the health department’s decision.

She says: “Benny Malakoane (Free State Health MEC) is in the court himself. He ate the taxpayers’ money, and he must still answer. But we want to work, we don’t want our patients to suffer. He should want the same.”

“Benny Malakoane (Free State Health MEC) is in the court himself. He ate the taxpayers’ money, and he must still answer. But we want to work, we don’t want our patients to suffer. He should want the same.”
Health workers still face prosecution

The #BopheloHouse94 community health workers have been on trial since April 2014. Their crime? Holding a peaceful night vigil in the hope that their political leaders will explain why they had all been dismissed. The group was convicted in October 2015 for violations of the archaic Regulation of Gatherings Act after being arrested during the vigil. The case has critical importance for the ability of all people in South Africa to safely exercise their constitutional right to protest.

The #BopheloHouse94 are CHWs from across the Free State. On 20 June, the appeal of the #BopheloHouse94 was postponed until August 8. The Judge ruled that both the appeal and the challenge on the constitutionality of that part of the Gathering Act would be heard together then.
SPOTLIGHT: FREE STATE HEALTH

#BOPHELOHOUSE94

JACOB MOKHANUHI – COMMUNITY HEALTH WORKER
I AM NOT A CRIMINAL

SUSAN KETSO MOLETSANE – COMMUNITY HEALTH WORKER
I AM NOT A CRIMINAL

CONSTANCE MOKOTELI – COMMUNITY HEALTH WORKER
I AM NOT A CRIMINAL

NTHAKO LEAH – COMMUNITY HEALTH WORKER
I AM NOT A CRIMINAL

SPOTLIGHT #15 – J uly 2016
Election-year clinic upgrades are welcome, but will they be enough?

Ufrieda Ho

All over the Free State things are buzzing with public works projects, but also with electioneering. It seems there are as many road works and infrastructure upgrades as there are election posters on walls and lampposts.

If election years are good for one thing, it’s that they make politicians scramble to look like they’re doing things. It’s had a positive outcome for the Batho Clinic on the outskirts of Bloemfontein. Back in 2014, NSP Review (now Spotlight) visited the clinic that had, for months, been in total disrepair. It had been vandalised and electricity cables had been stolen. Ceilings were collapsing, fridges were being used for storage and pharmaceutical supplies were left stacked in boxes, because no one could sort through the medicines in the dark. Nurses were using their cellphone torches to try to see patient files.

But this autumn Batho Clinic has had more than just a lick of paint – it’s had some serious upliftment and refurbishment. Extensive repair work has been done: new security upgrades are in place, there’s a patient-file storage unit and room, and there are improved seating and waiting areas.

Not far from Batho Clinic at Pelonomi Hospital, sections of the hospital have also undergone a contemporary-style revamp and construction is ongoing. Where work has been completed there are new decals, art work, water fountains for patients, and waiting areas that look more modern international airport than public hospital. Upgrades that can make a hospital or clinic experience more comfortable for patients, and help boost staff morale, are sorely needed.

By the end of May though, neither Batho Clinic nor Pelonomi Hospital had opened their doors or become fully operational. It makes the challenge of a properly integrated approach to managing hospitals and clinics an ongoing hurdle.

Better still, maybe Mmabana Clinic could also get a revamp, they say. It’s what would benefit them and their patients most.

By the end of May though, neither Batho Clinic nor Pelonomi Hospital had opened their doors or become fully operational.
Sitting on her stoop with her month-old baby, teenager Kekeletso Kikilame is unhappy and angry with the service she received at the JS Moroka Hospital when she gave birth to her child.

Cold water and cold attitudes at JS Moroka hospital

Ufrieda Ho

For five days after 18-year-old Kekeletso Kikilame had given birth, she could not wash herself or her newborn, as there was no hot water at the Dr JS Moroka Hospital in the Free State.

Worse though, says the teenager, is that the nurses had no empathy for her or the seven other women who were also giving birth in the hospital at the end of March.

“They kept telling us to get up and to go wash in the cold water. They didn’t even offer to warm up water for us,” says Kikilame, speaking through a translator at her home in the Thaba’Nchu.

She adds that the nurses ignored their pleas to close some windows when it was cold or to turn off lights when they wanted to sleep.

“You get cross, but you just keep quiet. Even today I’m angry with those nurses for how they treated me. Their attitude towards people is not right,” she says.

It was only five days after the birth, when her sister brought some flasks of hot water, that she was able to wash herself and her second-born, a boy she’s named Boikanyo.

Blood had clotted around her stitches making them painful to clean. She remembers being constantly anxious days after giving birth that she would develop an infection or that the health of her child would be compromised.

Sitting on her stoop with her family and neighbours she cradles her one-month old baby. She says she wishes she could sue the clinic. They should not be allowed to operate the way they do without consequences, she says.

At one time Dr JS Moroka Hospital was considered a top facility, locals say. It was especially well known as an excellent TB treatment facility, but that was many years ago. Today people call it a “mortuary” – you’re lucky if you come out alive, they say.

Kikilame says she’ll never want to go back there if she can help it. She says she’ll tell her friends to stay away. Nobody should have to be subjected to the nurses at that hospital, she says.

The rains may start to fill their dam, but more immediately it means they can fill their buckets to flush toilets or to store it for general use. A few extra buckets of water mean they can supplement their water supplies. Even though municipal water tankers now make the rounds in QwaQwa and the surrounding areas, the tanker rounds can be patchy.

Residents say there seems to be no fixed schedule. So if you are at work or at the shops you’ll miss the tankers. It means residents sometimes can’t plan properly for water collections. It forces those who can afford it to buy bottled water or borehole water from nearby farms. Alternatively they hope and pray for rain to collect a few buckets.

Adding to the constraints there are also reports that some tanker companies have stopped making their rounds because the municipalities have not paid them.

Most of QwaQwa’s water is supplied by the Fika-Patso dam but pumping from the dam stopped by the end of last year as dam levels dropped dramatically.

While the entire region is suffering and small businesses especially are struggling to stay open or to make enough profit, it’s hospitals and clinics that are most at risk operating without clean water. The risk of infection with compromised hygiene and poor sanitation are a very real concern.

Better resourced facilities like the regional hospital, the Mofumahadi Manapo Mopeli Hospital, have in recent months had the budget to buy water harvesting tanks, have portable toilets erected on the property and have been able to outsource their laundry services. Such measures have gone some way to keeping hospitals running and to keep patients safe, but there are no clear long-term or wide-scale strategies or contingencies for a prolonged drought.

At smaller clinics the public toilets are blocked or simply locked up. Staff facilities are closed to the public and staff members flush with collected rainwater. There are no alternative facilities even though patients have to wait long hours in the queues. Running water and flushing toilets are luxuries now.
Buthelezi EMS remains a problem and a mystery

Ufrieda Ho

The Free State’s health care system – in tatters in so many places – also has one recurring nightmare: Buthelezi Emergency Medical Services, to whom public emergency services have been outsourced.

Why did the province’s services needed to be outsourced or supplemented in the first place? Secondly, was Buthelezi the best company to land the tender, and, thirdly, why are the on-going complaints about the company’s service – since it got the contract at the beginning of 2014 – falling on deaf ears?

According to the Democratic Alliance’s questions put to MEC Benny Malakoane in August 2014, there were 106 ambulance and emergency services vehicles in the province. 56 were being serviced in workshops and 28 were about to be added to the fleet.

That year, Buthelezi EMS had been given the tender that comprises 47 ambulances for district and regional hospitals. Its staff was expected to have “basic life support and intermediate life support” training. This tender was also intended for emergency inter-facility transport, not for call-outs. According to a health department response to a DA question, billing is done according to the skill level of the paramedic attending to the patient. The contract is ongoing and by November of 2014 – the first 11 months of the contract was worth R32 million to Buthelezi.

Mariette Pittaway, DA member of the Free State Provincial Legislature said: “We still cannot understand why we were not servicing our existing fleet properly instead of spending that amount of money on an outsourced service.”

Pittaway says she’s never without fresh complaints about the services rendered by Buthelezi EMS. This is what worries her most. “We hear about ambulances arriving to pick up sick babies without incubators. We also hear that some clinics and hospitals are left without their blood-pressure machines and other equipment because they’ve had to hand them over to the ambulance staff. We’ve also heard how hospitals wait for up to two hours for an ambulance to arrive and, in one incident, the excuse for a delay in Ga-Frith was that the ambulance had a flat tyre and the driver had to wait for a spare tire to arrive. This kind of things is just not acceptable,” says Pittaway.

A matron who spoke to Spotlight had her own horror stories that mirror Pittaway’s. She said they routinely give surgical gloves and drip kits to the Buthelezi EMS paramedics who are simply not properly equipped to do the job. “They ask us for these basic things and then we get a bill for anything between R3500 and R4800 per patient,” she says.

In a letter written by a doctor in the Xhariep area more complaints emerge. The letter details how a Buthelezi ambulance vehicle had to drive back to Bloemfontein to fetch the correct oxygen pin index cylinder. Unfortunately the patient deteriorated and passed away at 12.30am. The ambulance arrived after the patient passed away,” the letter read.

It concluded: “We’ve had numerous problems with Buthelezi Ambulance Service in the past few months”.

In Bloemfontein this autumn, Spotlight visited the Buthelezi offices, situated in a house on the industrial outskirts of the city centre. Ambulances appeared to be serviced or repaired in the backyard. This is a clear compromise of safety standards for emergency medical services.

Outside Welkom, Spotlight saw Buthelezi ambulance vehicles and staff parked under trees. Tender stipulations require EMS private companies to have proper facilities where paramedics can take a shower, have a nap and recharge and refresh properly in-between assignments.

Pittaway says it’s clear that Buthelezi EMS is plagued with problems, yet they continue to be defended by the department of health and continue to cost Free State taxpayers millions of rands.

“We will continue to ask the questions because we don’t feel that we’ve been given good enough answers. We haven’t been able to pinpoint that the premier Ace Magashule and Health MEC Benny Malakoane have direct relationships with Buthelezi EMS, but we believe that how the tender was given out is problematic. We will keep up the pressure,” says Pittaway.

Spotlight’s questions to Buthelezi EMS remained unanswered by the time of going to print.
Robbed of their hospital in an National Health Insurance pilot district

Ufrieda Ho

The “bus stop” and the “slaughterhouse” – these are the nicknames locals give for the Nketoane Hospital in Reitz and the Dihlabeng Regional Hospital Bethlehem.

Both fall into the government’s National Health Insurance (NHI) pilot area of Thabo Mofutsanyane in the Free State, one of 10 pilot districts in the country. Pilot areas are meant to assess the readiness of facilities to rollout the NHI plans and also meant to uplift the needs of the most vulnerable communities in the country first.

Thabo Mofutsanyane is, according to Health Minister Aaron Motsoaladi’s assessments (which looks at socio-economic indicators, health service performance and financial and resource management), among the most needy in the country.

Locals in Reitz and the nearby location of Petsana say the problems began with the downgrade of Nketoane Hospital in 2002 from a 65-bed facility to a 45-bed facilities, to one that now accommodates just ten patients in a step-down facility. It is, for locals, a travesty. They feel they have been robbed of their hospital. Even though the hospital still runs a 24-hour maternity and casualty facility, it’s a shadow of its former self; a bus stop really, they say, where ambulances pick up patients to transport them nearly 50 kilometres away to the Dihlabeng Regional hospital in Bethlehem where they are supposed to be able to access a broader spectrum of health care services.

However, they don’t trust Dihlabeng Hospital. It’s a facility that will kill you before it heals you, they say. The slaughterhouse. Reitz locals, including those who live in the surrounding locations and townships, say they are often treated with disdain by nurses at Dihlabeng, with the common snipe of “Why don’t you just stay at your own hospital?”

A Petsana local, Victor Mlangeni, who also heads the United Residents’ Front, says that one of the major problems about being serviced by a hospital nearly 50km away is that people can’t visit their families easily. A taxi ride one-way costs R30. “They should have left that hospital as it was. Before it had all the services that we needed. Now it has nothing,” says Mlangeni.

Mlangeni says they’re also always given the run-around by the provincial authorities, who keep promising that things will improve. “In 2010 we were told that the Reitz Hospital would be back to normal within six months and we would have all the services back. But we waited and waited. In 2015 the government came again and said we would have to wait three more months.”

During his visit to the Petsana residents in 2016, Free State Premier Ace Magashule publicly gave his support to the residents over their concerns that there was shortage of doctors at Nketoane Hospital and that the vast distance between Nketoane and Dihlabeng, and even the Phakolong Hospital, were less than optimal. He promised to look into the matter personally. It’s half way into 2016: nothing’s changed and locals are still waiting for services to improve.

The Nketoane Hospital is essentially a storage facility now. There are currently two Cuban doctors at the hospital and eight professional nurses for the still-busy maternity section. It remains well-kept, clean and tidy, but it’s also strangely silent for what should be a busy medical hub.

Inside the hospital, empty beds are stacked on top of one other, filling up rooms. Whole wards stand empty and the operating theatres remain in darkness.
are stacked on top of one another, filling up rooms. Whole wards stand empty and the operating theatres remain in darkness. A hospital insider, who spoke on condition of anonymity, says everything was operational and in running order in the theatres, even though some of the equipment was old. But gradually it has been stripped, with working equipment shipped off from the hospital.

“When something has been taken and we can't get it back,” he says. “The interior of the hospital for years, says the morale among staff is low and he calls the NHPCA “a joke.”

The hospital, he says, has to submit plans based on the old information that it is a 45-bed hospital. It’s skewed data but no one has bothered to make the necessary adjustments. This means that the planning for the day-to-day running of the hospital is based on inaccurate information.

“When you work it out like that (at 45 beds) the hospital will always look like it is under-performing. It’s bad for the hospital and it’s bad of the morale of staff. The nurses are also not getting all their overtime pay and we aren’t getting any more staff because positions have been frozen.

“We are supposed to be an NHPCA hospital but we are not compliant with anything. It really is a joke and the Premier, the MEC and the HODs should all be fired.”

“This is also our community, we work here, we live here. All we want is to be able to serve this community properly and we can’t,” he says.}

SPOTLIGHT: FREE STATE HEALTH

When a good idea becomes good news: adherence clubs in the Free State

Ufrieda Ho

A simple well-managed idea is not only easing pressure on the Free State health care system and making HIV-positive patients’ lives easier – it also seems to be bringing down mortality rates amongst those with multi-drug resistant tuberculosis (MDR-TB).

Médecins Sans Frontières’ (MSF) adherence clubs have grown, in under two years, to include 11,300 members in the Mangaung district.

The idea was to create clubs of no more than 30 stable HIV patients (those with a viral load below 4000) who meet every two months for less than an hour to collect their ARVs. Is this correct? Doesn’t undetectable viral load normally mean under 50, or is there a new test?

Their medicines are pre-packed by a trained facilitator, so there’s no risk of queueing for an entire day only to be told there are no drugs or that there are too many people to be helped.

At the club meetings, patients are weighed, given TB screening and are given a general health quiz. They can discuss issues among themselves, and facilitators also have the opportunity to raise any specific matters, like a change in medicine packaging.

Members fetch their medicine and leave the clinic before the hour’s up. It means they can get on with their day with minimal disruption.

Once a year they undergo a blood test at a clinic. This test is scheduled by their club.

“It means there 11,300 people who are not clogging up the queues in clinic and hospitals. The patients are properly managed and it’s proving to be a system that’s working,” says Trudie Harrison, a coordinator at MSF/Mosa, the public benefit organisation affiliated to the Anglican Church that manages and facilitates the adherence clubs in the district.

“The aim now is to roll out to reach 21 clinics across the province in the next three years.”

The clubs are funded by Global Fund and Right to Care. Their support has translated into the purchase of four Wendy houses erected on clinic property. These structures serve as club meeting rooms and can also be used as extra facilities by the clinic.

“At some of our facilities we do two sessions a day. Our staff is also trained and salaried. They are not volunteers on a stipend and that model has been part of what’s made the clubs work.”

“This programme works because before, those with MDR-TB didn’t get treatment because they didn’t want to stay in hospitals. This way, the 24-month treatment can be administered by a nurse in the patient’s own home,” says Harrison.

Harrison says it’s too early to measure the success of the programme but she says that since October 2014 they have seen the mortality rate decline. It’s significant because MDR-TB patients only have a 50/50 chance of surviving.

The programme is aimed at reducing the rate of defaulting among MDR-TB patients and to reduce MDR-TB mortality rates.
Welcome to the twilight zone: fear and abandonment in the Free State’s health system

Mary-Jane Matsolo

Activist Mary-Jane Matsolo last year heard “saddening and horrific” stories from the more than 50 people who testified during the People’s Commission of Inquiry into the Free State Healthcare System. She recently entered the field to assess whether anything had changed. These are her notes.

First stop: Free State Psychiatric Hospital in Bloemfontein

I feel like I’ve been teleported into a scene from the X-files: the openness of the space – a huge, unoccupied, neglected piece of land, deserted buildings, dry, brown grass growing long all over the place. Nor a single patient or staff member in sight. The only sign of life is the odd security guard.

After the sixth circuit around the premises I’m convinced I’ve entered the twilight zone. I begin to imagine patients chained to their beds inside these empty buildings and I think about all those people we’ve reached out to for information about the health care system, but who felt out to for information about the health care system, but who felt

...we found a community caught in nostalgic memories of days gone by when they once had a fully functional hospital.

Next stop: Reitz

About four hours’ drive from Bloemfontein, we found a community caught in nostalgic memories of days gone by when they once had a fully functional hospital. Then abruptly, about 12 years ago, Nketoana Hospital was reduced to only two functions: the casualty unit and a partially functioning maternity unit. The residents still don’t understand the reasons why their beloved local hospital had its heart ripped out.

Now they have to travel to Bethlehem, about 55km away, only to be met by hostile nurses who, they say, discriminate against them by refusing to give us any information.

Then on to Nketoana Hospital

It was the next obvious and logical thing for us to do now: Nketoana Hospital. What we saw was extremely confusing. Here was a well-maintained, fully equipped hospital. It seemed set to be able to run like a well-oiled machine and yet most of it was simply shut down. Stepping into the theatre was like stumbling across the spot, on X-Files, where aliens are operated on – a place kept secret and which is only known about in files stamped “top secret” in some government official’s office somewhere. Equipment stood around collecting dust. It looked as though the hospital had been abandoned.

The houses in which, perhaps, doctors or staff members used to speak to us. This province is far from free, as its name implies. There are spooky looking houses here. Not patient wards: stand-alone houses in which, perhaps, doctors or matrons once lived. They’re creepy. It feels as though, like in a horror movie, matrons once lived. They’re creepy. It

Qwaqwa was next

There’s been no water here since February. The drought has hit hard. We’ve 91km from Bethlehem and our guesthouse has no water. How do hospitals and clinics function without water?

We were looking forward to hearing some of the wonderfully creative ways nurses and doctors were getting around this huge hurdle – caused by mother nature and not the provincial government, for us now – in their daily work.

We set out enthusiastically, eager to report on the innovations we were sure the staff would have come up with, but at the first clinic, the manager treated us with undisguised hostility, shutting us down and refusing to give us any information.

She referred us to the district clinic manager. The more we tried to explain our interest in how a facility functioned without water, the more hostile she seemed to get. She got up, escorted us out of her office and watched us suspiciously. She even followed us to the bathroom when we needed to use the toilet and accused us of inspecting her facility. She followed us to reception, obscuring that we sign the visitors’ register, and interrogating us about who we were and where we came from, even though we’d offered this information to her when we had introduced ourselves in her office.

We visited the district manager. We sat in her office for what felt like eternity while she refused to acknowledge our presence. Finally she spoke not to us, but down at us. It felt like we were in the principal’s office for bad behaviour. She gave us a firm lesson on having to make an appointment and about procedures that needed to be followed when seeking to talk to staff at clinics. We were told to consult Bophelo House – where the provincial health department is located in Bloemfontein – to gain a letter permitting us access to the clinics before coming to the facilities.

It was clear we were not going to get any information from these women. There was no getting through to them. It was as though they had been completely brainwashed. The cloak-and-dagger theme, the mystery and spookiness, was carried right through to the staff.

The good nurses – the one who

The paranoia is infectious.

As my travelling companion and I returned to the car, I said: "The not-so-free Free Stats." A complete stranger hooked on to our conversation, asking who we were and what we were doing there.

Is this some sort of government agent? Is someone following us now? The paranoia is infectious.

Mary Jane Matsolo is a Campaign officer for Treatment Action Campaign
In the early days of the AIDS epidemic, the high price of antiretroviral medicines meant many lives were unnecessarily lost. While the global AIDS movement managed to force lower prices for key ARVs, the wider battle has not yet been won. Today, many people with hepatitis C, various cancers, drug-resistant tuberculosis and other conditions still cannot get the medicines they need to survive. This article explains the how inequality extends to drug development.

There are two broad problems with the way society currently pays for medicines. The first, the innovation problem, is that we are not investing enough money and energy into finding treatments for diseases mostly affecting poor people. This is why most of our tuberculosis (TB) treatments today are more than fifty years old and not very good.

The second, the price problem, is that many of the medicines that are developed are sold at such high prices that people cannot afford them. This is why many people with hepatitis C cannot afford the highly effective new hepatitis C cures on the market. For these people the new cures might as well not exist.

The innovation problem

Last year, tuberculosis killed more people than any other infectious disease on the planet, including HIV. At 1.5 million deaths, it far outstripped headline-making outbreaks like Ebola (11,315 deaths in 21 months). Yet, in 2014 humanity invested less than US$700 million in TB research – only about a third of the two billion a year that the World Health Organisation estimates is required to bring an end to TB. Of this US$700 million, less than US$100 million was invested by the pharmaceutical industry. In fact, a number of large pharmaceutical companies have stopped doing TB research altogether. The first part of this problem is simple. Since most people needing TB treatment are poor, pharmaceutical companies see little potential profit in developing new TB treatments. Companies choose rather to invest in researching medicines that will sell in rich countries – medicines for diabetes, heart disease, or erectile dysfunction.

The second part of the problem is more puzzling: given that industry does not invest, one would expect governments to step in to fill the gap. However, with the exception of the United States, governments do not. While the BRICS countries (Brazil, Russia, India, China and South Africa) have over 40% of the global TB burden, they contribute less than 4% of global investment in TB research.

The price problem

When the patent system does deliver important new medicines, as it sometimes does, those medicines are often priced out of reach for many of the people who need it. So, for example, the breakthrough hepatitis C drug sofosbuvir is priced at US$84,000 for an 84-day course. Similarly, high prices mean that women in South Africa who need the breast cancer drug trastuzumab often can’t afford its R500,000 price tag.

“You are aware of the exploding prevalence of cancer around the world and in our own country. We have just moved in a circle. Just as the price of ARVs were unaffordable then, cancer drugs are devilishly unaffordable today. If no drastic action is taken today, we are going to be counting body bags like we are at war.”

Dr Aaron Motsoaledi, Health Minister of South Africa, 2016 budget vote speech.
WHERE DO COMPANIES PUT THEIR MONEY?

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<tr>
<th>Company</th>
<th>Total Revenue ($bn)</th>
<th>R&amp;D Spend* ($bn)</th>
<th>Sales &amp; Marketing Spend ($bn)</th>
<th>Profit ($bn)</th>
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*NOTE: Investment in R&D is often lower than profits and almost always lower than sales and marketing.

TB IS THE TOP INFECTIOUS DISEASE KILLER ON THE PLANET, CAUSING 1.5 MILLION DEATHS PER YEAR

The pharmaceutical industry claims to spend $137 billion on R&D per year. It spends less than $0.1 billion per year on TB research. TB is the top killer on the planet, causing 1.5 million deaths per year.

HOW THE US IS SPENDING ITS MONEY BILLIONS PER YEAR

The United States is one of the key countries obstructing progress on a proposed WHO R&D treaty/agreement. This is thought to be due to the potential cost of such a treaty – at most a few billion per year. The lack of political will to invest more in medical R&D should be seen in the context of the US’s $600 billion annual military budget.

How the US is Spending its Money billions per year

Military $609.3 billion
Education $102.2 billion
Surveillance $52.6 billion
Energy & Environment $44.8 billion
Science $29.8 billion

The “War on Drugs” $44.85 billion

The BRICS countries only contribute 3.6% of public funding to TB R&D though they account for 40% of TB-related deaths.

South Africa’s proposed nuclear expansion program is estimated at $65 billion (R1 trillion) over 15 years. This amounts to $4.3 billion per year. By contrast, the South African government invests less than $0.005 billion per year on TB research. TB is the top killer in South Africa.

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The “War on Drugs” spending is $44.85 billion.

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Companies argue that they have to ask these high prices to recoup their investment in developing the drugs and to fund their investment in developing new medicines. In recent years this argument has begun to wear very thin. A United States senate investigation in 2014 found that the pricing of sofosbuvir had nothing to do with how much it costs to develop the drug. Rather than basing prices on the investments made into a drug, companies are typically setting prices at levels that maximize profits — even if that means many people can’t access the drug in question.

At a more fundamental level, high prices charged by pharmaceutical companies have brought into question the basic social contract between the public and the pharmaceutical industry. The thinking is that the people, through our governments, grant patent monopolies to companies in return for investment in new medicines. However, enforcement of this social contract is very one-sided. While companies almost always get and maintain their patent monopolies, there is no enforcement of the expectation on companies to invest in research.

Typically, companies invest only between 8 and 18% of revenue in research and development (R&D), while they typically spend double on marketing and advertising. In addition, the way in which companies spend their R&D funds is completely non-transparent. All the available evidence suggests that we are not getting much bang for our buck in the current system where there is no obligation on industry to reciprocate high prices with high investment in R&D.

We have other options

Various solutions to these problems have been under discussion at the World Health Organization (WHO) over the last decade — with very little progress to show for it. In addition, in 2015 the Secretary General of the United Nations, Ban Ki-moon, convened a High Level Panel to look at exactly these problems. Even if the HLP comes up with strong recommendations, it will be up to governments to make those recommendations a reality. Some possible solutions include:

An R&D agreement or treaty

Given that industry is failing to invest in diseases that have an impact on poor people, governments have a responsibility to step in and fill that investment gap. One solution is an R&D treaty or agreement. Countries would all contribute to a central fund. Money in this fund would then be used to fund research in neglected areas like TB. This is a simple and workable solution. The only thing that is lacking is political will. Even if rich countries like the United States and Germany oppose such a treaty or agreement, there is nothing preventing other countries from going ahead without them.

Delinkage

When governments invest in research, they often do so in a way that allows companies to patent the products of that research. In this way, governments end up paying twice — once through research grants and again when paying high prices for patented medicines. If governments invest in a delinked way, they will not allow this double-payment to happen. In such a case, governments will fund research through grants and prizes and then ensure that all the research is paid for up front and that the research cost is “delinked” from the sale price of the eventual product. The so-called 3P Project (see our previous issue) is an example of a delinked model.

Bring balance to the system

International law allows for steps to be taken to balance the worst excesses or exploitation of patent monopolies. These balancing measures are commonly referred to as TRIPS flexibilities (Trade-Related Aspects of Intellectual Property Rights) and they include allowances for: compulsory licenses (overriding patents); only granting patents for truly innovative products and not for reformulations or new uses of old drugs; and for financial compensation in the event of unlicensed production.

“Rationing is the ultimate consequence of high drug prices. Unsurprisingly, this is unpopular and is causing a backlash. In a number of US states, politicians are seeking to pass legislation forcing drug companies to disclose more information about the cost of producing their high-priced remedies. There is even talk of capping prices. The industry argues that such caps would drive capital out of the industry, cutting innovation and ultimately harming patients. But that is a hard argument to sustain when companies such as Gilead and Vertex are earning gross margins of 90 per cent and share prices are sky high. Pharmaceutical innovation has been one of the great successes of the past century, improving the lives of millions immeasurably round the globe. But if the current dispensation is to continue, the industry must learn to price with greater restraint.” Financial Times, August 16, 2016.

We could compel all World Trade Organisation member countries to provide for at least 20 years of patent protection. The problem is that due to trade pressure from the United States Trade Representative, many countries have not written these TRIPS flexibilities into their national law — and if they have, they are often afraid to use them.

Doing away with pharmaceutical patents altogether

One of the remarkable things about the history of patents and medicines is that there is no evidence that providing increased patent protection around the world has led to greater medical advances. In fact, in the golden age of medical discovery from the 1940s to 1970s, much of the world did not offer any patent protection on medicines. There was also no increase in innovation following the TRIPS agreement in 1995, which compelled all World Trade Organisation members to provide for at least 20 years of patent protection. It would of course not make sense to simply remove the patent system and not replace it with anything else. The world, after all, is in desperate need of new medicines. Governments would have to redirect the money they would have spent on purchasing patented medicines to providing research grants and sponsoring prize funds for the development of new medicines. All indications are that such a transition would in fact see R&D spending increase dramatically — given how little industry currently spends on R&D as a percentage of revenue.

Our position is that the patent system is expensive. A decade-old study reckons that in 2005, without the temporary monopoly patents bestowed, America might have saved three-quarters of its $410-billion bill for prescription drugs. The expense would be worth it if patents brought innovation and prosperity. They don’t.

LOTTI RUTTER is a Senior Researcher for Treatment Action Campaign.

“Delinking is a simple and workable solution. The only thing that is lacking is political will. Even if rich countries like the United States and Germany oppose such a treaty or agreement, there is nothing preventing other countries from going ahead without them. Delinking is a simple and workable solution. The only thing that is lacking is political will. Even if rich countries like the United States and Germany oppose such a treaty or agreement, there is nothing preventing other countries from going ahead without them.” Financial Times, August 16, 2016.

The Econmist, August 8, 2015.

SOURCES

“Unprecedented Price Increases (US$)"}

Daraprim is used to treat toxoplasmosis, a possibly life-threatening infection in babies born to mothers with HIV and AIDS patients.

DARAPRIM $13.50 per

CYCLOSERINE $500 for 30 pills

DOXYCYCLINE $20 per bottle

ISUPREL $215

NITROPRESS $258 per

Nitropresside is used to treat congestive heart failure and life-threatening high blood pressure (hypertension)

Spotlight on intellectual property

Cycloserine is a drug used to treat MDR-TB.

Doxycycline is an antibiotic.

Isuprel is a heart medication.

The Economist, August 8, 2015.
A cure for HIV: Are we getting any closer?

Dr Thomas A. Rasmussen & Professor Sharon R. Lewin

Antiretroviral therapy (ART) has revolutionised the lives of people living with HIV and in many countries, life expectancy for someone living with HIV is now almost the same as someone not living with HIV. But ART is not a cure. When ART is stopped, the virus rebounds within a few weeks in almost all infected individuals, even after many years of suppressive therapy. Understanding where and how HIV persists on ART and using these insights to develop therapies, which will ultimately enable us to cure HIV infection, or allow people living with HIV to safely stop ART with the virus staying under control, remain key goals in HIV research.

Over the past decade, there has been a substantial increase in our understanding of where and how HIV persists when someone is on ART. It is now clear that integration of the HIV genome into long-lived resting cells is a major barrier to a cure. This state is called HIV latency. But virus can also persist on ART in other forms. In both monkey models of HIV and in HIV-infected individuals on ART, virus has been found in T follicular helper cells, which are found in a specialised compartment in the lymphoid tissue. These cells are found in a part of the lymph node where penetration of immune fighting cells, or cytotoxic T-cells is limited. In some tissues, penetration of ART may not be optimal, which could contribute to persistence. Finally, there is also some evidence that, in at least some individuals and in some sites, the virus may still be replicating at very low levels.

To date, there has been just one case of a cure for HIV, which occurred in the context of haematopoietic stem cell transplantation (HSCT) for leukaemia with HIV-resistant donor cells. HSCT is clearly not a feasible curative strategy for HIV, but we have learnt here that complete eradication of HIV is theoretically possible. Similar approaches have been tried, but no others have yet been successful and all six individuals receiving a similar transplant died of infection or cancer relapse within 12 months of transplantation.

Other case reports have confirmed that HSCT, even from a regular stem cell donor, can drastically reduce the frequency of infected cells, but when ART was subsequently discontinued, virus still rebounded off ART, although it took months and not weeks to rebound. These cases demonstrate that although reducing the frequency of latently infected cells might delay time to viral rebound, there is a need for continued effective immune surveillance against HIV to keep whatever remains in check.

Using gene therapy to either make a cell resistant to HIV or to literally remove the virus, remain key goals. One example of gene therapy is to eliminate CCR5 and make cells resistant to HIV. Clinical trials of gene therapy to eliminate CCR5 and make cells resistant to HIV was safe, but there remains much work to be done to increase the numbers of gene-modified cells. Other work, which still is at the stage of test-tube experiments, uses gene scissors to target the virus itself. This approach might be trickier than targeting CCR5 as the virus can rapidly mutate and change its genetic code so that the gene scissors no longer work.

Several years ago, French investigators described that post-treatment control was possible in up to 15% of individuals described that post-treatment control was possible in up to 15% of individuals treated within months of infection. These data remain a little controversial as in other cohorts, post-treatment control was far less common. We still don’t fully understand where and how HIV persists on ART and using these insights to develop therapies, which will ultimately enable us to cure HIV infection, or allow people living with HIV to safely stop ART with the virus staying under control, remain key goals in HIV research.
Cure research is likely to benefit from the very significant investment in vaccines that have been developed to protect people from getting infected, some of these vaccines could work in cure too – for example vaccines that potentially stimulate cells that are programmed to kill infected cells or alternatively highly effective antibodies, called broadly neutralising antibodies, that can also trigger killing of an infected cell. These vaccines are now being investigated in the setting of clinical trials in infected individuals on ART.

There have been some spectacular recent advances in the treatment of some cancers using drugs that boost the immune response – called immune checkpoint blockers. These drugs reinvigorate exhausted T-cells so they can move in to action – against cancer cells and in the same way, against HIV-infected cells. These drugs, one that blocks CTLA4 and another that blocks PD1 are now in clinical trial in HIV-infected patients being treated for different cancers. Another way to boost the immune system is to trigger a very primitive immune response designed to respond to infections. These drugs are called toll-like receptor (TLR) agonists. In monkeys, TLR7 agonists, currently being developed by Gilead, stimulate latently infected cells and an effective immune response leading to a modest reduction in infected cells. Clinical trials are now underway in HIV-infected individuals on ART.

Now, four years after the launch of the 2012 International AIDS Society (IAS) Global Scientific Strategy Towards and HIV Cure, we have had some successes and failures. We now have a clearer idea of where virus persists on ART, and 90% of patients on ART are on ART, and 90% of patients on ART would have viral levels of less than 0.1% per annum, the long-term HIV prevalence rate of less than 0.1% per annum. Notably, the models were generally quite optimistic about the extent to which ART would reduce the number of new infections.

Even if we accept this definition of HIV elimination, mathematical models are not conclusive about whether universal ART eligibility and high rates of HIV testing and ART uptake (so-called “test and treat” strategies) would lead to elimination. In a systematic comparison of several different models that were applied to South Africa, Eaton et al found that even if ART coverage among 15-49 year olds was constant at 90% per annum, and 90% of individuals need to be on ART, and 90% of patients on ART need to be virologically suppressed.

But how likely is HIV elimination? Central to answering this question is mathematical models, which attempt to predict the future based on observed historical trends in HIV prevalence, and based on assumptions about the effect of different HIV prevention and treatment strategies on HIV transmission. This article briefly reviews some of the recent modelling studies that have attempted to answer this question, and discusses some of the limitations and uncertainties associated with modelling.

The first point to note is that the term ‘HIV elimination’ is a misnomer. Most frequently, modelling studies refer to ‘virtual elimination’, which is conventionally defined as an adult HIV incidence rate of less than 0.1% per annum. Even if we accept this definition of HIV elimination, mathematical models are not conclusive about whether universal ART eligibility and high rates of HIV testing and ART uptake (so-called “test and treat” strategies) would lead to elimination. In a systematic comparison of several different models that were applied to South Africa, Eaton et al found that even if ART coverage among 15-49 year olds was constant at 90% per annum, the long-term HIV prevalence rate of less than 0.1% per annum would not drop below 1.7% (assuming a relatively high ART coverage and a near-normal life expectancy on ART). This is still an appreciable HIV prevalence, even by the standards of many countries in West Africa.

The first point to note is that the term ‘HIV elimination’ is a misnomer. Most frequently, modelling studies refer to ‘virtual elimination’, which is conventionally defined as an adult HIV incidence rate of less than 0.1% per annum.
HIV infectiousness (in all cases by 90% or more), though a subsequent systematic review of observational data estimated an average reduction of only 64%. It was also subsequently found that almost all the models had underestimated the HIV prevalence that was measured in a South African household survey, conducted after the initial model projections were published. Although this points to the fallibility of mathematical modelling, it is perhaps more important to note that the models generally did not show that HIV elimination was a likely outcome, despite relying on the side of optimism. A question that naturally follows is whether a ‘test and treat’ strategy might achieve HIV elimination when combined with other HIV prevention strategies. In a recent study, we attempted to address this question for South Africa by projecting future HIV incidence trends using a wide range of different intervention scenarios. This study predicted that – given the current uncertainty around HIV prevention and treatment programmes in South Africa – the virtual elimination target of 0.1% would be reached by 2035 in only 2% of scenarios (Figure 1). The model also predicted that although South Africa would probably reach the first 90% target by 2020, the second and third 90% targets were quite unlikely: in only 0.4% of scenarios were all three targets met. Solid lines represent mean of model estimates. Dashed lines represent 95% confidence intervals (taking into account uncertainty regarding future epidemiological parameters). Shaded grey area represents virtual elimination threshold. Source: Johnson et al

This study also assessed which epidemiological parameters it would be most important to focus on in order to reduce HIV incidence. The most important parameter was the rate of virological suppression in ART patients: for every 10% increase in the fraction of ART patients who are virologically suppressed, it was predicted that there would be a 14% reduction in the average annual number of new HIV infections. This implies that increasing rates of virological suppression in South African ART patients from the current level of around 77% to the 90% target would achieve an 18% reduction in HIV incidence. Other parameters that were significant included the rate of condom use in non-cohabiting relationships, the introduction of intensified risk-reduction counselling for HIV-positive adults, and the uptake of medical male circumcision. Interestingly, the timing of the change to universal ART eligibility was only the 5th-most important parameter. This suggests that the recent change to universal ART eligibility is not by itself likely to have as dramatic an impact on HIV incidence as many other interventions. The case of South Africa stands in stark contrast to the case of Denmark, the subject of another recent modelling study. In this study, it was estimated that in 2009 the HIV incidence among Danish men who have sex with men (MSM) was 0.14% per annum, very close to the virtual elimination threshold of 0.1%. Although the fraction of HIV-positive adults in Denmark who were diagnosed was very similar to that estimated in South Africa (around 80% in 2013), the fraction of diagnosed individuals on ART was 92%, and the fraction of ART patients who were virologically suppressed was 98% – both well ahead of South Africa (Figure 2). As the authors of this study note, Denmark is exceptional. In many other high income countries, there has been a resurgence in HIV incidence among MSM, despite increasing levels of ART coverage. This resurgence is often attributed to risk compensation and ‘disinhibition’, i.e. increased levels of sexual risk behaviour due to reduced fear of HIV in the era of highly effective therapy – and perhaps also reduced public messaging around safe sex as the HIV response has become increasingly medicalised. Taken together, these results suggest that treatment alone is not going to end the HIV epidemic, although it might be possible in concentrated epidemic settings with exceptionally high levels of virological suppression. It will be important not to neglect the ‘traditional’ HIV prevention strategies in the pursuit of the 90-90-90 targets, and the allure of new prevention approaches should not detract from the need to sustain and improve existing programmes. But even with co-ordinated strengthening of existing programmes and introduction of new prevention approaches (such as universal ART eligibility and pre-exposure prophylaxis), it is unlikely that virtual elimination will be achieved in hyper-endemic settings such as South Africa within the next 20 years. Even if ‘elimination’ is achieved, there would need to be continued high levels of HIV testing and HIV prevention messaging over the longer term if a resurgence in HIV were to be avoided. Achieving true elimination will require fundamentally new technologies such as HIV vaccines. Until we have these in place, HIV elimination needs to be seen as an aspirational ideal rather than a practical target.

It will be important not to neglect the ‘traditional’ HIV prevention strategies in the pursuit of the 90-90-90 targets, and the allure of new prevention approaches should not detract from the need to sustain and improve existing programmes.
Pills containing tenofovir and emtricitabine

The most effective form of pre-exposure prophylaxis (PrEP), according to the currently available evidence is a once-daily pill containing the two antiretroviral drugs tenofovir and emtricitabine. However, the efficacy of this combination pill has varied substantially in different studies. This variation appears to be linked to two factors: the level of treatment adherence and the nature of the population in which the drug is being tested. In almost all PrEP studies, people who take the pills as prescribed have had significantly better outcomes than people who do not.

Tenofevir/emtricitabine combination has generally had better results in studies of men who have sex with men (MSM) than in studies conducted in heterosexual women. These differences appear in part to be due to biological differences between the rectum and the vagina – but also seem to reflect better adherence among MSM – at least in the studies conducted so far.

In general though, a pretty clear picture has formed in recent years. If people take tenofovir/emtricitabine daily they are much less likely to contract HIV. With good adherence the risk is dramatically reduced, but there is some recent evidence suggesting that even with perfect adherence the risk is not reduced to zero. We thus recommend that whenever possible tenofovir/emtricitabine PrEP should be taken in addition to using condoms.

The World Health Organisation and the Southern African HIV Clinicians Society recommend the use of daily tenofovir/emtricitabine for people at high risk of HIV infection. We fully support this recommendation.

What about the gel and the ring? Apart from the tenofovir/emtricitabine combination, tenofovir as a pill alone, tenofovir in a gel form, and a vaginal ring containing the ARV dapivirine have also been tested. None of these interventions has been as effective as the tenofovir/emtricitabine pill taken daily. While there was great excitement about 7% tenofovir gel a few years ago, this excitement has evaporated following a series of disappointing trial results. As with PrEP pills, adherence seems to play a crucial role in how well the gel works. In the key studies conducted...

Both the World Health Organisation and the Southern African HIV Clinicians Society recommend the use of daily tenofovir/emtricitabine for people at high risk of HIV infection. We fully support this recommendation.

Conclusion: The evidence shows that oral TDF-FTC is effective for the prevention of HIV infection. The evidence for efficacy in men who have sex with men is particularly strong. The efficacy of PrEP appears to be highly dependent on good adherence. Adherence among women in sub-Saharan Africa taking part in clinical trials was generally very low. We recommend oral TDF-FTC as PrEP for all people at high risk of acquiring HIV.

Pills containing tenofovir and emtricitabine

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oral TDF

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<tbody>
<tr>
<td>Partners PrEP</td>
<td>Heterosexual men and women in a serodiscordant relationship</td>
<td>44% couples</td>
<td>Daily oral TDF associated with a risk reduction of 57% (95% CI; 44 to 61; P&lt;0.001)</td>
<td>A detectable level of benefit (vs. non-detectable) is associated with a relative risk reduction of 86%</td>
</tr>
<tr>
<td>VOICE</td>
<td>Women from sub-Saharan Africa aged 18-45 y.o.</td>
<td>5029 women</td>
<td>-4.0% with TDF (hazard ratio for infection: 1.49; 95% CI; 0.77 to 2.95)</td>
<td>n/a</td>
</tr>
</tbody>
</table>

Conclusion: The evidence on oral TDF is mixed and not as strong as the evidence for oral TDF-FTC. We do not recommend the use of oral TDF as PrEP.

1% TDF Microbicide Gel

<table>
<thead>
<tr>
<th>Study Name</th>
<th>Study Population</th>
<th>Size of Study</th>
<th>Key Findings</th>
<th>Comments/Our Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAPRISA 004</td>
<td>Urban and rural South African women aged 18-40 y.o.</td>
<td>889 women</td>
<td>Acquisition of HIV was 5.6% per 100 woman-years (CI; 4.2 to 7.1) in the active group vs. 9.3% per 100 woman-years (95% CI; 6.9 to 12.7) in the placebo group (IRR; 0.61; 95% CI; 0.40 to 0.94; P=0.071)</td>
<td>n/a</td>
</tr>
<tr>
<td>VOICE</td>
<td>Women from sub-Saharan Africa aged 18-45 y.o.</td>
<td>5029 women</td>
<td>14.5% effectiveness (hazard ratio: 0.85; 95% CI; 0.61 to 1.21)</td>
<td>n/a</td>
</tr>
<tr>
<td>FACTS 001</td>
<td>South African women aged 18-30 y.o.</td>
<td>2059 women</td>
<td>61 infections in the TFV arm and 62 in the placebo arm (incidence rate ratio (IRR): 1.20; 95% CI: 1.0 to 1.4)</td>
<td>n/a</td>
</tr>
</tbody>
</table>

Conclusion: The evidence suggests that 1% TDF gel does not work for the prevention of HIV infection in women. We do not recommend the use of 1% TDF gel.

Dapivirine Ring

<table>
<thead>
<tr>
<th>Study Name</th>
<th>Study Population</th>
<th>Size of Study</th>
<th>Key Findings</th>
<th>Comments/Our Assessment</th>
</tr>
</thead>
</table>
| ASPIRE     | Women 18 y.o.    | 2620 women | Overall efficacy: 27% (95% CI; 1.1 to 46; P=0.05)  
Efficacy among women 25 y.o. to 44: 32% (95% CI; 1.0 to 57; P=0.001)  
Efficacy among women under 25 y.o.: 10% (95% CI; 41 to 43; P=0.04)  
Efficacy among women 18-29 y.o.: 27% (95% CI; 1.8 to 43; P=0.05) | n/a | The ring was only modestly effective in this study for the prevention of HIV infection. There is uncertainty over the findings, since the bottom end of the confidence interval is close to 0 and the p-value is on the border of statistical significance. |
| The Ring Trial | South African and Ugandan women | 1959 women | Reduced the risk of HIV-1 infection by 30.7% (95% CI; 0.9 to 55.5; P=0.0001)  
A 53% (95% CI; 3.5 to 55.9%) reduction in HIV infection in women older than 21 years | n/a | The ring was only modestly effective in this study for the prevention of HIV infection. There is uncertainty over the findings, since the bottom end of the confidence interval is close to 0 and the p-value is on the border of statistical significance. |

Conclusion: While both these studies showed moderate levels of efficacy, the statistical details in both cases create substantial uncertainty. Given this uncertainty and given that oral TDF-FTC has shown greater efficacy, we do not recommend the use of the Dapivirine ring for HIV prevention at this time.

Treatment vs PrEP

While it is clear that governments and donors should invest both in treatment for people living with HIV and in PrEP, there may be situations where policy-makers may feel forced to choose between the two due to resource constraints. A number of modelling studies have teased out the impact these different interventions are likely to have on new infections.

- A 2014 study by Alister and colleagues concluded that universal ART treatment, with either a marginal or a broad scale-up, was cost effective, cost saving, and provided more health benefits than general PrEP. The study evaluated the population health outcomes and cost-effectiveness of implementing expanded ART treatment and oral PrEP in South Africa. Different strategies, in which ART, PrEP, or both were scaled up to 25%, 50%, 75%, or 100% were assessed. In general, the strategies involving a scale-up of ART for all people with HIV averted more infections than the strategies involving an equal scale-up of PrEP for all eligible people. The best strategy considered was a 100% scale-up of universal ART (which averts 75% of new infections without any PrEP) and PrEP focused on high-risk populations (which averts 57% of all new HIV infections without any ART scale-up). This strategy costs only US$160 per quality-adjusted life year (QALY) gained and was the most effective of all strategies at preventing new HIV infections.

- A 2012 modelling study by Cremin at al came to similar conclusions. They found that “at a population-level maximal cost-effectiveness is achieved by providing ART to more infected individuals earlier rather than providing PrEP to uninfected individuals. However, early ART alone cannot reduce HIV incidence to very low levels and PrEP can be used cost-effectively in addition to earlier ART to reduce incidence further. If implemented in combination and at ambitious coverage levels, medical male circumcision, earlier ART and PrEP could produce dramatic declines in HIV incidence, but not stop transmission completely.”

Apart from the type of cost/benefit analysis described above there is also an important ethical consideration. There is a moral responsibility first to treat people living with HIV – given that since the Strategic Timing of Antiretroviral Treatment (START) trial we know that all treatment for their own health. KRISTANNA PERIS is an undergraduate student at Northeastern University and an intern at the TAC.
The future of antiretroviral treatment

Polly Clayden & Simon Collins

We are in a very exciting time for HIV treatment (ART) for three reasons.

1. South Africa, the country with the biggest HIV treatment programme, has agreed to make ART available to everyone who is living with HIV.
2. An important new HIV drug – called dolutegravir – is expected to be available soon in low-income countries at a low price.
3. Other developments may lead to treatment with only one or two drugs – instead of three, and two-monthly injections – instead of pills.

Over 17 million people with HIV are receiving ART worldwide. This is less than half of the over 36 million people living with HIV.

In 2015, the Strategic Timing of AntiRetroviral Treatment (START) and TEMPRANO studies showed the benefit of ART at all CD4 counts – even when higher than 500. This led the World Health Organisation (WHO) to recommend that everyone with HIV should start treatment. South Africa has also recently adopted this “treat all” strategy, doubling the number of HIV-positive people eligible for treatment.

The WHO also decided to recommend one main first-line combination for everyone in low- and middle-income countries (LMIC) including South Africa. This is a single pill with efavirenz (EFV), tenofovir disoproxil fumarate (TDF) and either emtricitabine (FTC), or lamivudine (3TC). This simplified first-line ART in low and middle-income countries including South Africa. This is a very good combination. It is good at reducing even high viral load and it has been used by millions of people for over ten years. However, a newer combination might have fewer side effects and therefore might be better. It will also reduce viral load quicker and have less risk or drug resistance. This will use dolutegravir instead of efavirenz and a new version of TDF called TAF.

Will everyone switch to the new combination straight away?

Even though studies have already proven the advantages of the newer drugs, there are still some gaps in the studies. The needs of HIV-positive people are different in LMIC. This is because there are larger populations of women of childbearing age, children, and people with TB and other co-infections. Data from using these newer drugs universally on these groups of people are not yet available. The studies that approved dolutegravir and TAF were run in high-income countries. Information about the dose and compatibility with other antiretrovirals were mostly gained from studies in men – and not from studies in women in countries like South Africa.

What are the new drugs and what studies are still needed?

Dolutegravir

The integrase inhibitor dolutegravir (DTG) has many properties that make it an important potential drug for use in LMIC:

- It only needs a 50mg once-daily dose. This means pills can be much smaller and cheaper to produce.
- It has a very high barrier to drug resistance.
- It is good at reducing viral load quickly and keeping it undetectable.
- It has few side effects.
- It has the potential to be low-cost.
- It is easy to co-formulate with other HIV drugs in a single pill.

DTG was superior to EFV in the so-called SINGLE (1) trial in people receiving first-line treatment. Other DTG studies have shown it to be superior – or non-inferior – to other commonly used antiretrovirals in high-income countries both in first- and second-line treatment. But DTG studies have not yet included significant numbers of people who would be treated in LMIC. The main studies for DTG had approximately 80% men and few women.

Over 17 million people with HIV are receiving ART worldwide. This is less than half of the over 36 million people living with HIV.
SPOTLIGHT SCIENCE: TREATMENT

non-white participants. They enrolled very few people co-infected with other diseases (a few with hepatitis B and none with TB or malaria).

People with drug resistance were not included (especially with resistance to NNRTIs (nucleoside/nucleotide reverse transcriptase inhibitors)).

Information about treating HIV/TB coinfection with a DTG-based regimen is limited.

A Phase 1 study in HIV-negative people showed that the TB drug rifampicin lowers drug levels of DTG. This study suggested a higher DTG dose will overcome the interaction – ie. taking 50 mg twice a day rather than once a day. Another study will give results on this strategy later in 2016. Other studies are looking at drug levels in people with TB. They could show that the current 30mg once-daily dose might be okay, despite the lower levels. Information about DTG in pregnant women is also limited — although this is always the case with every new HIV drug. Early results suggest DTG drug levels in pregnancy are similar to those in non-pregnant adults but that they are lower compared with postpartum.

A small number of women became pregnant in the DTG studies and early-use programme, and numbers of use during pregnancy will increase in high-income countries. So far for a 18-week/trimester and 18 second/trimester exposures have been reported to the Antiretroviral Pregnancy Registry (APR) of 31 July 2015. From these data there were none and one congenital defect respectively.

Several studies are planned or ongoing to look at DTG use in pregnancy.

Tenofovir alafenamide (TAF)

TAF is a new version of tenofovir and is always the case with every new HIV drug.

As with DTG, there is currently less information about TAF with TB treatment and during pregnancy. Very few studies have used TAF in combination with DTG.

TAF is currently the major driver of cost in LMIC generic-first-line combinations.

The Clinton Health Access Initiative (CHAI) estimates that TAF could lower the cost of first-line ART by as much as 50% in South Africa this would allow a US$500 million reduction on the annual cost of ART by 2018.

As with DTG, there is currently less information about TAF with TB treatment and during pregnancy.

How studies in South Africa will help global treatment

One very important study will start this year in South Africa. This will provide important new results for both dolutegravir and TAF.

The study — called ADVANCE will include approximately 1050 HIV positive people to compare three combinations for first-line treatment.

1. DTG/TAF plus FTC
2. DTG/TDF plus FTC
3. EFV/TDF plus FTC

The results will be used to decide whether DTG/TAF/FTC (or 3TC) becomes the preferred first-line in WHO guidelines.

The main results will be the proportion of people with undetectable viral load after 48 weeks, though the study will run for two years.

There will also be sub-studies that will help to address the potential issues with TB coinfection and with pregnancy.

These three study groups will clarify when dolutegravir and TAF are best used — including with each other.

The DTG/TDF/FTC arm is included in the case drug interactions between TAF and rifampicin result in different side effects or in cases there are differences in pregnant women. Having data to support DTG use with TDF will still be able to show benefits over current standard of care.

The efavirenz group is the current standard of care in all LMIC. FTC and 3TC are interchangeable in almost all guidelines. Because this combination has been so widely used, the WHO needs a large new study to prove whether newer drugs are better before guidelines can be changed.

If successful, at least one generic manufacturer has already agreed to produce the new DTG/TAF/FTC FDC at a lower price than EFV/TDF/FTC.

The following three drugs are also worth watching out for:

• A new entry inhibitor (called fostecuvir)
• A drug from a new class – a maturation inhibitor – currently called BMS-955176
• Very early results from a compound called EFA. This drug might be available from a slow release depot that only needs to be replaced once a year.

Finally, tentative results from several small studies suggest that the properties of dolutegravir might enable this drug to be used in a unique way.

Early reports suggested that some people might be able to reduce their combination to a two-drug combination of dolutegravir plus 3TC. Even more surprising was that most people kept their viral load undetectable for up to six months after switching to dolutegravir as a single drug.

Together with the discussions earlier in this article on the cost of ART and the importance of wider access to ART, if larger studies show this reduced drug strategy to be safe, this will have global implications for how ART is used.

strategy to be safe, this will have global implications for how ART is used.
The era of viral load is here

Sharonann Lynch

Viral load testing measures the amount of HIV virus (HIV RNA) in a person’s blood. It is the optimal method for identifying antiretroviral therapy (ART) treatment failure (defined as an HIV viral load greater than 1000 copies/mL), because it is more sensitive and has a higher positive predictive value than CD4 cell count and other clinical indicators.

Diagnosing treatment failure as soon as possible is important, so that HIV-positive people can switch to an effective second-line regimen that suppresses the virus and keeps them healthy. Viral suppression also benefits communities, since it significantly lowers the risk for HIV transmission. Viral load monitoring is more likely to keep people alive and in care than other testing. When used with counselling and other support services, it increases adherence to ART. The latest World Health Organisation (WHO) guidelines recommend that viral load testing occur six months after initiation of ART and at least annually thereafter.

Expanding access to viral load monitoring will be crucial for achieving the third goal articulated in the UNAIDS ‘90:90:90’ treatment targets, which calls for 90% of people receiving ART to have durable viral suppression (defined as an HIV viral load below 50 copies/mL) by 2020.

There are other expenses: Roche’s test has a global commercial ceiling price of US$94.0 per test, while the price of Siemens’ product ranges from US$54-72. Increasing demand is an effective method for lowering prices, as it allows countries to take advantage of market competition. In South Africa, where viral load monitoring has already been rolled out, a successful competitive tender process was run that reduced the price per viral load test to under US$5. The price of viral load testing can be defrayed by savings from monitoring CD4 cell count less often, while access to viral load testing is expanded, although countries should be cautious about scaling back CD4 cell testing before viral load monitoring has been effectively rolled out. WHO guidelines suggest that monitoring CD4 cell count can be safely reduced or eliminated for people who are clinically stable on ART and who live in areas where routine viral load monitoring is consistently available. Eight countries so far have adopted this recommendation and eliminated routine CD4 cell testing for people on antiretroviral treatment.

Some of the logistical challenges to scaling up viral load monitoring can be addressed by new technology. Although plasma samples are the “gold standard”, they require strict temperature control and rapid transport to laboratories. This makes it difficult to implement plasma-based testing in settings with limited laboratory capacity and decentralized care systems, but dried blood spot (DBS) samples can be used to avoid these challenges. DBS is the best sample option for scale up in resource-limited settings, because samples are stable at ambient temperatures for long periods of time, are lightweight, and are easy to transport. Currently available DBS tests have lower specificity and sensitivity than plasma-based tests, and most testing platforms have not yet received regulatory approval for use with DBS, but improved products are expected in the near future. Viral load testing is primarily performed by trained technicians in laboratories. Point-of-care and near point-of-care tests are becoming increasingly available. These eliminate the need to transport samples, and people can get their test results faster than with laboratory-based tests. But point-of-care tests can be more expensive, have lower throughput capacities, and require more training for health care workers in decentralized care settings. No matter what type of test is used, a well-developed system for tracking and notifying people of their results is crucial for effective monitoring of viral load.

Countries with limited existing capacity can begin by using viral load tests to confirm suspected cases of treatment failure identified by clinical or immunological criteria. Viral load monitoring can then gradually be scaled up to routine use for all people on ART. Routine testing can also be phased in gradually, by targeting specific populations or geographic areas. For example, viral load testing can be implemented first in health facilities that have greater laboratory capacities, or can be selectively offered to high-risk groups such as children and pregnant women. Routine viral load monitoring cannot become a reality without a significant investment in awareness and education. By itself, access to routine viral load monitoring does not guarantee effectiveness and utilisation, unless it is provided with best practices such as enhanced adherence counselling (EAC) for people with high viral loads. People living with HIV must have information about the meaning and importance of viral load monitoring and viral suppression, how frequently testing is required, and how viral load monitoring differs from CD4 testing, in order to create demand for viral load monitoring. Education and training should also be provided to healthcare workers, to improve their knowledge of and motivation for providing routine viral load testing. Efforts to scale up viral load monitoring should include civil society organizations that raise awareness and influence donors and governments. To this end, the International Treatment Preparedness Coalition has developed an ‘Activist Toolkit’ to empower advocates to campaign for greater access to viral load monitoring.

A recent MSF report titled Making viral load routine on implementation of the viral load treatment “cascade” across MSF-supported sites in four African countries confirms that further scale up is required. Coverage of routine viral load monitoring at these sites ranged from 0% to 86%, while rates of provision of viral load (EAC 57-70%) and the likelihood of tests being repeated after EAC intervention (23-68%) also varied. Rates of switching to second-line ART regimens after persistent high viral load results were low at all sites (10-38%), however higher rates were achieved at sites using point-of-care tests.

Ultimately, the effectiveness of any scale up strategy will be context-dependent and programs should be designed to reflect local capacities and challenges, including financial resources, health system infrastructure, disease burden, and populations. Collaboration between stakeholders – including governments, donors, clinicians, people living with HIV and civil society – is required to overcome barriers and expand access to viral load testing for all people receiving HIV treatment.

The report ‘Making viral load routine’ can be found here: http://www.msfaccess.org/makingviralloadroutine

SHARONANN LYNCH is with the Médecins Sans Frontières Access Campaign.
Clinical trials and scientific discoveries give renewed hope for an HIV vaccine

Professor Lynn Morris, Professor Carolyn Williamson & Dr Kathy Mngadi

We are at a pivotal point in the pursuit of a vaccine against HIV. Two large efficacy trials will begin in 2016, both aimed at testing whether antibodies can protect against HIV infection.

The first is a classical vaccine approach based on active immunization while the second will test a passively administered broadly neutralizing antibody. Results from these trials are expected in 3-4 years’ time at the earliest. There have been significant advances in the laboratory that are delivering new vaccine concepts which are being fast-tracked for testing. On the eve of AIDS 2016 we reflect on the progress we have made, since we last met in Durban in 2000, towards the development of the ultimate game-changer for the HIV epidemic: an HIV vaccine.

New vaccine trials in populations at risk of HIV infection

A major global effort has focused on building on progress of the first partially effective vaccine that was tested in Thailand in 2000, which protected 31% of people from HIV infection. Although protection has been linked to the presence of antibodies that bind to a part of the viral envelope (known as variable loop 2 or V2), the reason why this vaccine worked is still under investigation. HIV is a highly diverse virus and so the Thai vaccine was redesigned to target clade C viruses that are dominant in southern Africa.

The trial will recruit 5 400 people in South Africa at risk of HIV infection, who will receive a total of five vaccinations over a year. The vaccine is comprised of two parts, a canarypox vector prime (ALVAC) and a protein boost, both of which contain fragments of HIV that stimulate the body to mount an immune response to HIV. If, after 3 years, at least 50% of people are protected, the vaccine will be considered successful and rolled out for general use. Even at this level of protection, this vaccine could have been a partial victory for the epidemic. The decision to move forward with this vaccine was dependent on results from a smaller trial showing that it is safe and able to stimulate the right kinds of immune responses. As all criteria were met, the large vaccine trial known as HVTN 102 was given the green light in April 2016 and will start in November of this year. It has taken seven years of planning and the formation of the Pox-Protein Public-Private Partnership (P5) to get to this point. P5 comprises the South African Medical Research Council, the National Institute of Allergy and Infectious Diseases (NIAID), the HIV Vaccines Trial Network (HVTN), the Bill and Melinda Gates Foundation, the US Military HIV Research Program and vaccine manufacturers (Sanofi Pasteur and GSK). A similar plan to test this vaccine in large efficacy trials is also planned for Thailand using the original vaccine that is based on circulating strains in that country.

Another vaccine, developed by Janssen Pharmaceuticals and which showed encouraging results in animal studies, is also on track for large scale human testing (possibly in 2017). This vaccine will also use a prime boost approach, however, in this case, it will comprise an adenovirus 26 (Ad26) vector and a protein boost. The vaccine contains mosaic HIV genes that are designed to target viruses from around the world and will be evaluated in southern and east Africa, as well as in Asia. If, after 3 years, at least 50% of people are protected, the vaccine will be considered successful and rolled out for general use.

Other promising vaccines that are still in the animal phase of testing include a subunit vaccine based on the HIV envelope protein gp120, which elicits antibodies to many antigens. This vaccine includes a number of epitopes that are predicted to be conserved across clades of HIV. A new vaccine using a similar approach is being developed in the US and is being tested in two Phase II trials.

Ramping up to AMP

Probably the most remarkable development in the vaccine space has been the advent of passive immunization for HIV prevention. This new approach was made possible as a result of the discovery of broadly neutralizing antibodies that have the ability to kill a large number of HIV viruses from different clades. A vaccine with high efficacy is likely to require antibodies with this kind of activity, but to date no vaccine has managed to do this. However, the isolation of these antibodies from infected people, and the ability to make them in large quantities in the laboratory, has allowed us to directly test them. This is the concept behind the ‘AMP’ (antibody mediated protection) study, which started in the Americas and Africa in 2016 and will enrol a total of 4 200 people at risk of HIV infection. This trial is being done as a collaboration between the HVTN and the HIV Prevention Trials Network (HPTN). A monoclonal antibody, called VRC01, will be directly infused into the bloodstream of human volunteers to determine whether it can protect against HIV infection and what levels of antibody are needed. The antibodies will decay over time, so repeated infusions will be needed to keep the levels high enough to provide protection. The use of antibodies as passive immunization is a well-established approach to provide protection from other infectious diseases such Rabies and Respiratory Syncytial Virus. This monoclonal antibody, while providing invaluable information for vaccines, is not planned as an end-product as there is a pipeline of better, more potent antibodies which can be used alone, or in combination to increase the chances of killing more viruses. Other modes of antibody delivery, including subcutaneous injections and gene therapy, are also being explored. It is important to remember that passive immunization provides temporary protection, unlike a vaccine which generally gives life-long protection.

How basic research is helping us make better vaccines

Until now, a major hurdle in the development of an HIV vaccine has been the inability to make proteins that look like those on the virus particle and are suitable for manufacture. The trimeric viral envelope spike which is the target of neutralizing antibodies is a highly complex protein that has eluded structural biologists for decades. With new technologies this puzzle has finally been solved and initial studies have shown that these laboratory-generated envelope proteins do induce better neutralizing antibodies. There is a major push in laboratories in small experimental trials to see if they can stimulate neutralizing antibodies in human volunteers. How to elicit broad and potent neutralizing antibodies remains the biggest challenge in vaccine research. This is because viruses have evolved cunning ways to avoid detection by the immune system. It has an extraordinary ability to mutate and in addition the HIV envelope cloaks itself with sugars (glycans) making it difficult for antibodies to reach vulnerable sites. This plasticity allows HIV to evade the neutralizing antibody response, like a perpetual game of cat and mouse. Furthermore, some HIV infected people make broadly neutralizing antibodies after many years into the infection. This, together with the unusual features of HIV antibodies, highlights how difficult it is for the human immune system to make these types of protective antibodies.

The next decade is likely to bring more research breakthroughs. The pipeline of HIV vaccines remains elusive, we have come a long way since Durban 2000. Unlike vaccines for Ebola (and possibly Zika), HIV presents a far bigger scientific challenge. That we still do not have an effective HIV vaccine despite tremendous efforts is testimony to the infectious nature of this disease. The next decade is likely to bring more significant advances and we await the outcome of the two large efficacy trials with anticipation. Successful products would, without doubt, bring about a major paradigm shift in the fight against the global AIDS epidemic.

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Are we meeting the NSP targets?

Compiled by Kristanna Peris & Marcus Low

The National Strategic Plan for HIV, STIs, and TB 2012-2016 (NSP) set a number of ambitious targets for South Africa to have reached by 2016. While 2016 data will not be available for another year or two, the available data (mostly from 2014 and 2015) is nevertheless illuminating.

It is worth keeping in mind that our knowledge, particularly of HIV, has changed substantially since the current NSP targets were set. We now know that all HIV positive people must be provided with antiretroviral treatment irrespective of CD4 count. Most people have also accepted the UNAIDS 90-90-90 targets – targets that make the targets in the current NSP seem timid and outdated. As is clear from the table, many of the current NSP targets will not be reached. Yet, we know that to end AIDS and TB we will have to set much more ambitious targets in the next NSP. There is no two ways about it – the task ahead of us is huge.

NOTE: The SANAC comments in the right-hand column was taken from SANAC’s 2016 NSP Progress Report on NSP 2012-2016.

SOURCES:
### HIV Incidence
- **Indicator:** Actual number of new HIV infections in the population
- **How Often is Measured:** Quarterly
- **Target by 2016:** 1.47 (2012-13)
- **Statistics:** 0.7% (2005: Health Indicators; Health Systems Trust)
- **2014/15:** 0.87% (2014: Joint Review of HIV, TB & PMTCT Programmes in South Africa Main Report April 2014)
- **Was the Target Met?** No
- **SPOTLIGHT AND SANAC COMMENTS:** 18% decline based on updated and corrected baseline data. HIV incidence remains above the desired target for the adult population - SANAC

While the downward trend in HIV incidence is not rapid enough - there is hope that increasing treatment coverage, the continued rollout of VMMC, together with other prevention methods may lead to continued reductions. - Spotlight

### HIV Mortality
- **Indicator:** Success of HIV and TB Programmes
- **How Often is Measured:** Annually
- **Target:** 518,404
- **Statistics:** 4.36% (2014: Joint Review of HIV, TB & PMTCT Programmes in South Africa Main Report April 2014)
- **2014/15:** 218,1%
- **Was the Target Met?** No
- **SPOTLIGHT AND SANAC COMMENTS:** According to UNAIDS (2013), HIV mortality has declined. This is a major achievement due to improved reporting. - SANAC

HIV mortality is still much higher than hoped for in 2018. - Spotlight

### MTCT rate (6 weeks and 18 months)
- **Indicator:** Success of the Prevention of Mother to Child Transmission Programme, by determining the percentage of babies born HIV positive
- **How Often is Measured:** Annually
- **Target:** 15% (6 weeks); less than 5% (18 months)
- **Statistics:** 1.5% (6 weeks); less than 5% (18 months (2015) SANAC’s 2016 NSP Progress Report on NSP 2012-2016
- **2014/15:** 2% (6 weeks); 5% (18 months)
- **Was the Target Met?** Yes
- **SPOTLIGHT AND SANAC COMMENTS:** Target exceeded for MTCT at 6 months. Target met for MTCT at 18 months (at follow-up). - SANAC

Very little data exists at the 18 month failure to track this data will make it almost impossible to measure the success of the programme or set new targets for the future. - Spotlight

### Number of people reached by prevention communication at least twice a year
- **Indicator:** Reach of communications
- **How Often is Measured:** Every 3 years
- **Target:** 1 Billion
- **Statistics:** Quarterly
- **2012-2016:** 99%
- **SPOTLIGHT AND SANAC COMMENTS:** The 2014 National Stigma Index marks the baseline. - SANAC

These figures are based on outdated treatment guidelines. When new WHO and SA treatment guidelines are used treatment coverage drops to around 50%. - Spotlight

### Patients alive and on treatment
- **Indicator:** Retention in care
- **How Often is Measured:** Quarterly
- **Target:** 1 Billion
- **Statistics:** 12mo=94%, 24mo=91%, 36mo=82%, 48mo=70%, 60mo=60%
- **2015:** 1 Billion
- **Was the Target Met?** No
- **SPOTLIGHT AND SANAC COMMENTS:** According to UNAIDS (2013), HIV mortality has declined. This is a major achievement due to improved reporting. - SANAC

HIV mortality is still much higher than hoped for in 2018. - Spotlight

Retention on ART is below target for each cohort due to absence of a unique identifier - high chances of under-reporting. In addition unrecorded viral loads done lead to under-reporting. - SANAC

In addition to factors identified by SANAC, health system dysfunction, long queues, medicines stockouts, lack of community healthcare workers and lay councillors likely contributes to these shockingly poor retention in care figures. – Spotlight

### Male condom distribution
- **Indicator:** Reach of condom distribution programme
- **How Often is Measured:** Quarterly
- **Target:** 1 Billion
- **Statistics:** 239,799,877 (2015); SANAC’s 2016 NSP Progress Report on NSP 2012-2016
- **2014/15:** 723,799,877
- **Was the Target Met?** No
- **SPOTLIGHT AND SANAC COMMENTS:** 18% decline based on updated and corrected baseline data. HIV incidence remains above the desired target for the adult population - SANAC

While the downward trend in HIV incidence is not rapid enough - there is hope that increasing treatment coverage, the continued rollout of VMMC, together with other prevention methods may lead to continued reductions. - Spotlight

### MTCT rate (6 weeks and 18 months)
- **Indicator:** Reach of contraception programmes
- **How Often is Measured:** Quarterly
- **Target:** 508,404
- **Statistics:** 1,600,000
- **2012-2016:** 1 Billion
- **Was the Target Met?** Yes
- **SPOTLIGHT AND SANAC COMMENTS:** More than 90% achievement towards target. - SANAC

According to UNAIDS (2013), HIV mortality has declined. This is a major achievement due to improved reporting. - SANAC

HIV mortality is still much higher than hoped for in 2018. - Spotlight

### Number of men circumcised, medically (MMC) and traditionally (TMC)
- **Indicator:** Reach of male circumcision (MC) programmes
- **How Often is Measured:** Quarterly
- **Target:** 1,600,000
- **Statistics:** 239,799,877 (2015); SANAC’s 2016 NSP Progress Report on NSP 2012-2016
- **2014/15:** 508,404
- **Was the Target Met?** No
- **SPOTLIGHT AND SANAC COMMENTS:** According to UNAIDS (2013), HIV mortality has declined. This is a major achievement due to improved reporting. - SANAC

HIV mortality is still much higher than hoped for in 2018. - Spotlight

In addition to factors identified by SANAC, health system dysfunction, long queues, medicines stockouts, lack of community healthcare workers and lay councillors likely contributes to these shockingly poor retention in care figures. – Spotlight

### Percent of people per year who become eligible and receive ART
- **Indicator:** Coverage of the ART programme
- **How Often is Measured:** Quarterly
- **Target:** 82%
- **Statistics:** 79% (2015: Joint Review of HIV, TB & PMTCT Programmes in South Africa Main Report April 2014)
- **2015:** 82%
- **Was the Target Met?** No
- **SPOTLIGHT AND SANAC COMMENTS:** According to UNAIDS (2013), HIV mortality has declined. This is a major achievement due to improved reporting. - SANAC

HIV mortality is still much higher than hoped for in 2018. - Spotlight

More than 9% achievement towards target. - SANAC

These figures are based on outdated treatment guidelines. When new WHO and SA treatment guidelines are used treatment coverage drops to around 50%. - Spotlight

### Number of people reached by prevention communication at least twice a year
- **Indicator:** Reach of communications
- **How Often is Measured:** Every 3 years
- **Target:** 1 Billion
- **Statistics:** 82% (2012: SANAC’s 2016 NSP Progress Report on NSP 2012-2016)
- **2012-2016:** 99%
- **Was the Target Met?** No
- **SPOTLIGHT AND SANAC COMMENTS:** According to UNAIDS (2013), HIV mortality has declined. This is a major achievement due to improved reporting. - SANAC

HIV mortality is still much higher than hoped for in 2018. - Spotlight

These figures are based on outdated treatment guidelines. When new WHO and SA treatment guidelines are used treatment coverage drops to around 50%. - Spotlight

### Stigma Index
- **Indicator:** Trends of stigma and discrimination experienced by those with HIV or TB
- **How Often is Measured:** Every 2 years
- **Target:** 50% Reduction
- **Statistics:** 35% external stigma among HIV+ 43% internal stigma among HIV+ 36.3% TB related stigma (2015); SANAC’s 2016 NSP Progress Report on NSP 2012-2016
- **2015:**
- **Was the Target Met?** No
- **SPOTLIGHT AND SANAC COMMENTS:** The 20th National Stigma Index marks the baseline. - SANAC

Unfortunately the results of the National Stigma Index cannot reliably be generalised to the entire population. These figures should be treated with caution. - Spotlight
Percent of registered TB patients who tested for HIV

- Success of smear positive TB treatment
  - 82.5% (2015): Department of Health: Annual Report 2015
  - Quarterly: 85%
  - Gradual improvement towards the 2016 and international target - SANAC

- TB Case Fatality Rate
  - 7.4%: District Health Barometer 2014/15
  - Annually: 50% reduction from 8.4% to 4.2%
  - Slow progress towards 2016 NSP target - SANAC

Number of all newly registered TB cases who are HIV positive, expressed as a % of all newly registered patients

- Information about the epidemics of both TB and HIV. It gives an indication of the degree of overlap in the epidemics and the contribution that is making to the TB epidemic in any given setting
  - Average co-infection rate: 56.6% (2014): District Health Barometer 2014/15
  - Annually: 90%
  - Exceeded NSP target of 90% by 2016 - SANAC

TB case registration

- Number of TB cases detected and started on treatment
  - 567,000,000 (Total TB cases notified (2014)) WHO Global TB Report
  - Annually: 35%/100,000
  - Slow progress towards 2016 NSP target - SANAC

TB case detection rate

- An indication of the proportion of all incident TB cases that are diagnosed, reported, and started on treatment
  - 68% (61-77%): WHO Global TB Report
  - 68% (2014): Health Indicators: Health Systems Trust
  - Annually: >85%
  - A decline from set baseline, unlikely to meet target set for 2017 - SANAC

Percent smear positive TB cases that are successfully treated

- The proportion of notified TB patients who die while on treatment
  - 82.5% (2015): Department of Health: Annual Report 2015
  - Quarterly: 85%
  - Gradual improvement towards the 2016 and international target - SANAC

TB incidence

- Number of new and relapse of TB (all forms) estimated to occur in a given year
  - 519,000,000 (2014): District Health Barometer 2014/15
  - 800/100,000 (2013): South African Health Review 2014/15
  - Annually: 49/100,000 (50%)
  - Annual TB incidence declined by 15% but remains well above set target for 2016 - SANAC
  - With the exception of scaling up IPT and increased ART coverage, South Africa’s TB prevention efforts are grossly insufficient. Active case-finding and infection control in public spaces (including correctional and healthcare facilities) remain neglected. - Spotlight

TB mortality

- Success of HIV and TB programmes
  - 66/100,000 in HIV negative population
  - 18/100,000 in PLHIV
  - 44/100,000 in HLV negative population
  - 9/100,000 in PLHIV
  - 69/100,000 (2010): Health Indicators: Health Systems Trust
  - Annually: 25/100,000
  - TB mortality rate decreased from 50 to 44 per 100,000 in the HIV negative population. TB mortality in PLHIV decreased from 168 to 134 per 100,000 from 2012 to 2014. There is a decline compared to the baseline but the target of a 50% reduction has not been reached - SANAC/SANACAN
  - According to the WHO TB report, TB mortality rates have decreased slightly (from 59 in 2012 to 44/100,000 in 2014). The progress is insufficient and TB remains a crisis. - Spotlight
Today the future of the Treatment Action Campaign (TAC) is not as certain as it should be. Donor priorities have changed and funding for AIDS is rapidly diminishing. However, the challenges have not gone away. Denialism may be virtually dead but HIV and TB face a new set of complex challenges. The TAC continues to receive reports of and engage with challenges of medicine stockouts, weakening health systems, growing evidence of poor adherence, and the spread of multi drug resistant-TB.

You need TAC now more than ever!

With its thousands of volunteers located across the country, often in the poorest and most disadvantaged areas, the TAC is the eyes and ears of the response to HIV and the South African health system as a whole. Through its unblemished national and international reputation it is the only organisation with a voice loud enough to keep the AIDS programme on track in South Africa.

If the TAC is forced to further scale back its operations, then before long the response to HIV in South Africa will return to the unacceptable level of many other responses to diseases of the poor. Do we want that?

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Since it was founded on Human Rights Day in December 1998, the TAC has:

• Helped drive down the price of antiretroviral drugs to affordable levels;
• Won a Constitutional Court case that opened the door to a nationwide programme to prevent mother-to-child transmission of HIV; MTCT is now at less than 3%.
• Broken the resistance of official AIDS denialism and brokered the first serious national strategic plan on HIV and TB;
• Mobilised communities continually to promote take-up of antiretroviral treatment and tracked and tackled the roll out meticulously, pointing out every problem, stock-out and shortage;
• Helped to set up organisations like the Joint Civil Society Monitoring Forum, the Budget and Expenditure Monitoring Forum, and now the Stop Stockouts Project; and
• Campaigned to draw attention to the collapse of provincial health systems in the Eastern Cape and Free State and created pressure to fix them.

Please help us to keep these campaigns alive. TAC gives you lives for money. Donate to the TAC today.

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OPENING OF THE GLOBAL VILLAGE
2.45pm – 4.45pm
Global Village ICC
TAG General Secretary Anelisa Yawa will welcome the global community of activists to South Africa.

ACTIVITY MEETING
6.30pm – 8.30pm
Royal Hotel (7-minute walk from the ICC).
Join this first activist meeting to share plans, coordinate activities and discuss ways to demand a new era in the AIDS response at the AIDS conference. We will provide detail of the preparations for the mass march on Monday 18th July as well as other plans.
Each day we will chair an activist meeting in the mornings following on from this. Time and location to be determined.
For more information, contact Lotti at: lotti.rutter@tac.org.za

MONDAY 18 JULY
MARCH FOR “QUALITY TREATMENT FOR ALL”
10am to 3pm
Meet: King Dinuzulu Park
Royalt: Dr Ab Xuma Street, Walnut Road or Stalwart Simelane Street.
Programme of speeches: Memmo Obopape, Opposition, Dr Ben Knipe, MEC, and Rupert Carlisle.
In 2000, thousands of people from across the world marched together at the International AIDS Conference in Durban, South Africa. The march was a watershed moment in the global AIDS response. This July, once again, we will take to the streets of Durban but, this time the AIDS response is waning, our unfinished business.
This July, once again, we will take to the streets of Durban. We cannot let people die, who can live.
This march will be the opening act of the Global Village.

OPENING OF THE CONFERENCE
7.30pm – 9.30pm
TAG National Chairperson Nkensia Moyo will deliver a powerful speech at the opening of the conference that demands a new era in the AIDS response.

TUESDAY 19 JULY
TAC/SPOTLIGHT/SECTION27 PRESS CONFERENCE
TIME: 10am – Media Centre
The latest edition of the NSP Review (now renamed Spotlight) will be launched at the conference. This will have background on the primary health care who will talk about the state of the ANC HIV programme.
TAG, OXFAM, STOPAIDS, MSF, ICN, and ActionAid for Work for People, not for Profit
5pm – 6.30pm
Southern Sun Elangeni/Maharani Hotel, Marine Parade Road
Good health should be a basic and essential asset at human beings. Without it we cannot learn or earn. We cannot contribute meaningfully to our families or communities. It is a fundamental human right. If the system we have created to develop the medicines we require to obtain in price so high that they are unaffordable to those in need - and ignore the illnesses afflicting millions of people – then that system is failing. The Treatment Action Campaign (TAG), OXFAM and STOPAIDS will highlight how this system can be changed to work for the benefit of people. It will focus on the submissions and discussions around the UN Secretary General’s High-Level Panel on Access to Medicines and ways forward.
Light dinner and drinks will be provided.
For more information contact Lotti at: lotti.rutter@tac.org.za

THURSDAY 21 JULY
TREATMENT NETWORKING ZONE – IS THE INTELLECTUAL PROPERTY SYSTEM BROKEN?
Join the Treatment Action Campaign (TAC), STOPAIDS, the International Treatment Preparedness Coalition (ITPC), and the Brazilian Interdisciplinary AIDS Association (ABIA) on Thursday 21st July in the Treatment Networking Zone in the global village in a session of seminars that look into the intellectual property system and ask if it is providing us with the medicines we need?
Treatment activists will discuss the current system showing how it fails to develop medicines for illnesses affecting the poor – and where medicines do exist, how they are often priced out of reach.
This will be interactive workshops that provide a space for learning and networking.
For more information contact Lotti at: lotti.rutter@tac.org.za

JOHNNY Clegg CONCERT AND FUNDRAISER FOR TAC
Elangeni Hotel, Small Parade
7pm
Iconic music legend Johnny Clegg live and unplugged!!! Buy a ticket and support the TAC...come and hear veterans of the struggle reflect on 26 years of activism since our first gathering in Durban in 2000. An evening of reminiscing, letting our hair down and reflecting on some of the good in the world. Join us for “The Greatest Zonne” with Iconic music legend Johnny Clegg live and unplugged!! Buy a ticket and support the TAC...come and hear veterans of the struggle reflect on 26 years of activism since our first gathering in Durban in 2000. An evening of reminiscing, letting our hair down and reflecting on some of the good in the world. Join us for “The Greatest Zonne” with Iconic music legend Johnny Clegg live and unplugged!! Buy a ticket and support the TAC...come and hear veterans of the struggle reflect on 26 years of activism since our first gathering in Durban in 2000. An evening of reminiscing, letting our hair down and reflecting on some of the good in the world.
For more information and tickets info@johnnyclegg.com

FRIDAY 22 JULY
CHALLENGING INTELLECTUAL PROPERTY RIGHTS IN HIV & HCV
11am-12.30pm
ICC Session Room 7
In this session the Fix the Patent Coalition and South African Law Reform Commission will discuss the patent system and its detrimental impact on the primary health care.
For more information contact Catherine at: c.smith@tac.org.za

Please visit the TAC/SECTION27 stands in the global village and the activist space to get latest details on activists that will be present at events. Also follow us on Twitter and Facebook for latest updates @tac and @SECTION27news

Please note that this FAQ section, the information about the next event, as well as the community space to get latest details on activities that will be present at events. Also follow us on Twitter and Facebook for the latest updates @tac and @SECTION27news

All details were correct at the time of going to press. Please check www.tac.org.za and www. spotlight24.org.za for updates.

Activists guide to Durban
FRIDAY & SATURDAY 16 & 17 JULY
WORKSHOP AND MARCH: STEPHEN LEWIS FOUNDATION GRANDMOTHERS’ GATHERING AND GOOD MARCH
July 15 WORKSHOP: 14:00, (afternoon presentation)
Garden Court, 167 O R Tambo Parade, Marine Parade, Durban
July 16 MARCH: Gather at 08:00 to start march 09:00
The march route will not be from the Victoria Park, opposite the Seventh Day Adventist Marine Parade Hotel (located on OR Tambo Parade) but will originate from the Comrades Marathon start point on Marine Parade Street, then cross Sylvestor Ntuli Road continuing on Monty Nkanye Road, then cross Shilpake Road and will right turn on Dr A B Xuma Street, then turn right onto Walnut Rd and end at the caravan site on the south side of the ICC.
The Grandmothers’ Gathering conference (July 16 – 17) will educate and inform grandmothers who are taking care of their positive grandchildren or who have lost grandchildren to HIV-infected related illness.
On July 15, TACistas will present a workshop on how grandmothers can help their OVC to deal with the grief and loss of their loved ones. On July 16, there will be a Grandmothers’ Gogo March and reading of the Grandmothers’ statement.
How information: barbarab@tac.org.za

SUNDAY 17 JULY
30 BY 20: WHAT WILL IT TAKE?
8.30am-5.30pm
Royal Hotel (7 minute walk from the ICC).
A global activist meeting on winning the third battle in the war for affordable HIV treatment for all: Join HealthGAP, TIPC, MSF, and the Treatment Action Campaign (TAC). We will share updates and informative reports and exchange political analyses regarding the barriers and activations at multiple levels in order to bring about equitable and affordable access to HIV treatment for all.
For more information contact: mpofu@section27.Org.Za

Former TAG General Secretary and international AIDS activist Vyajika Dubula will take the gloves off as a civil society insider.

SECTION27 Executive Director and AIDS activist Mark Heywood will pull us into the main action.
Join us for “The Greatest Debate” at Durban 2016.

TAG, OXFAM, STOPAIDS, MSF, ICN, and ActionAid for Work for People, not for Profit
5pm-6.30pm
Southern Sun Elangeni/Maharani Hotel, Marine Parade Road
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Are you tired of all the hot air “End of AIDS” rhetoric? Do you feel some speakers at AIDS2016 need to be “subbed” off the bench? Need to be red carded? This is your chance to show your displeasure and join activists in saying “PHANSI RHETORIC!!” (Down with rhetoric)...Hold up this red card whenever you had have ENOUGH of the blah blah blah...