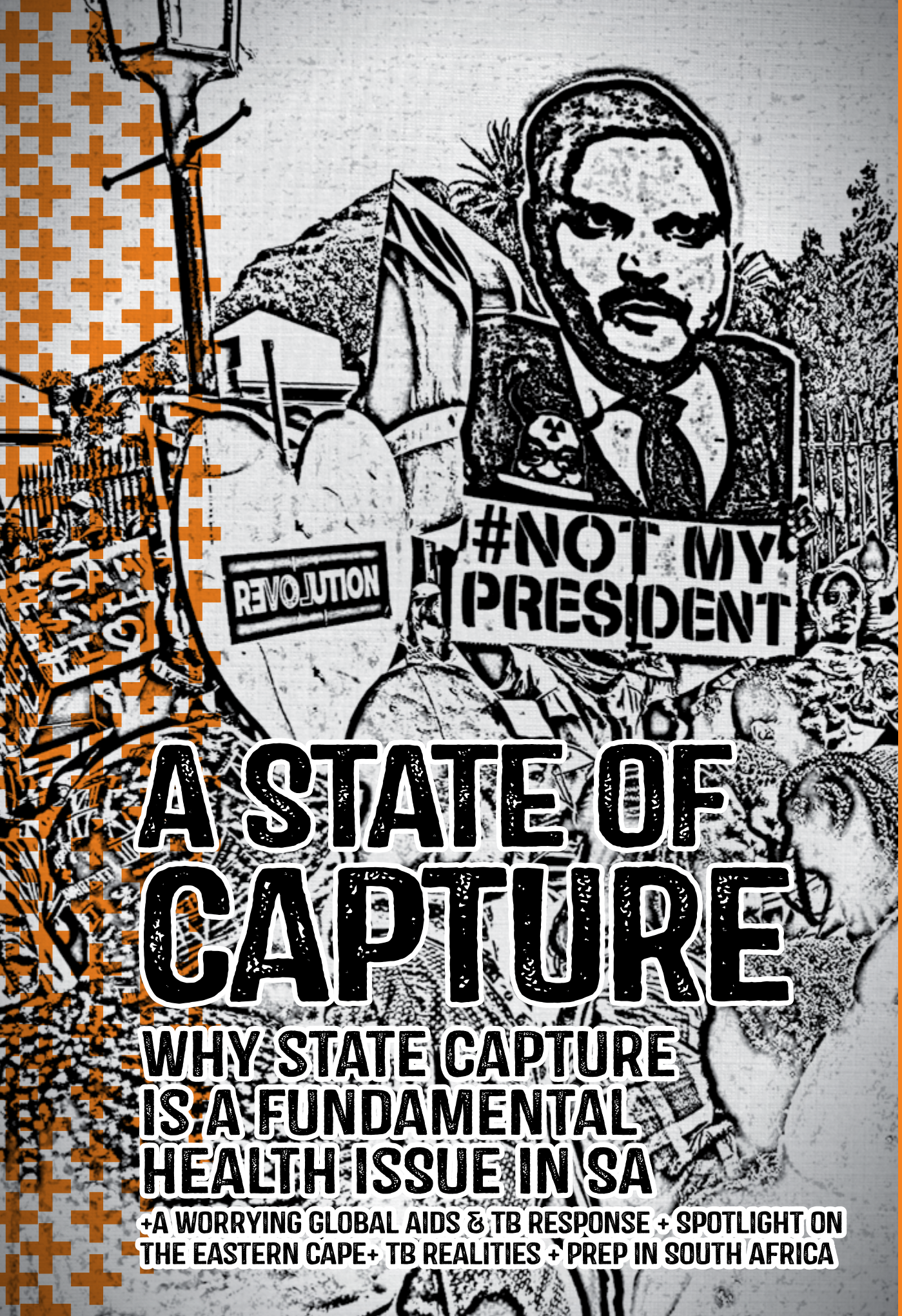

A STATE OF CAPTURE

WHY STATE CAPTURE IS A FUNDAMENTAL HEALTH ISSUE IN SA

+A WORRYING GLOBAL AIDS & TB RESPONSE + SPOTLIGHT ON THE EASTERN CAPE+ TB REALITIES + PREP IN SOUTH AFRICA

spotlight
on the state of health in South Africa
incorporating the *NSP Review*
Edition #4 – December 2017

spotlight
the state of health in South Africa
incorporating the NSP Review
Edition #16 – December 2016

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A high level ministerial meeting took place in Moscow where the delegates focused on TB and what needs to be done to turn the tide. Read this report from the frontline.
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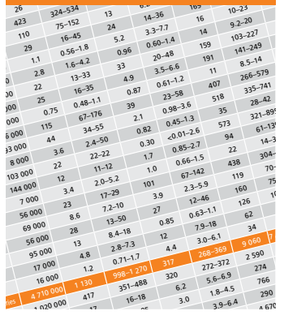

We unpack the findings, the numbers, from the latest WHO TB report. It is a report that reveals that too many people are still dying of TB worldwide, and specifically in South Africa.
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Cover image: South Africans march on parliament in April 2017 to protest state capture and corruption. Story on page 7.

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EDITORIAL INDEPENDENCE

The opinions expressed in *Spotlight* do not always reflect the views of TAC or SECTION27.

TAC
TREATMENT ACTION CAMPAIGN

The Treatment Action Campaign (TAC) advocates for increased access to treatment, care and support services for people living with HIV, and campaigns to reduce new HIV infections. Learn more about the TAC's work at www.tac.org.za.

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GLOBAL HIV & TB RESPONSE

The state of the global HIV and TB response in December 2017

On the eve of World AIDS Day 2017, Spotlight asks a series of activists, researchers, doctors and powerful persons in the HIV and TB worlds what they think.

I am tired *– to the point of despair – of all the congratulatory public raptures about the progress against HIV and AIDS. How could we not have made progress? It's been thirty-six years, for heaven's sake: we were bound to move forward. Instead indulging in an orgy of self-hypnotic success, we should be demanding to know how it's possible that up to 19 million people still don't have treatment; that women and adolescent girls continue to bear the brunt of the pandemic's assault; that key populations are demonised by fossilised governments, so that prevention and treatment are never available; and that we're in a staggering funding crisis, the sure outcome of which is even greater morbidity and mortality. Where is the political and multilateral leadership that can decisively and forever turn the tide? We should all be raging against the profusion of fatuous voices.*

Stephen Lewis, co-director, AIDS-Free World.

HIV and TB continue to be major global public-health issues*, with an estimated 37 million people living with HIV and an estimated 10.4 million with TB. The vast majority of people living with HIV and TB are from the low and middle-income countries, and the majority of them are public healthcare users. We can't afford to lose this battle; political rhetoric without action won't win this battle. The only revolutionary step towards ending HIV and AIDS is to invest more resources in public health care, and have the political commitment and will required to overhaul public healthcare systems. Only a functional, well-maintained, well-resourced public healthcare system that will serve the people – irrespective of their class, sexual orientation, financial status and of other discriminatory laws – can take us to where we want to see ourselves with our global response to HIV and TB.*

Anele Yawa, General Secretary, Treatment Action Campaign.

A bittersweet trajectory: *We are in an epoch in which the HIV epidemic continues in an unremitting manner, eradicating the promise of a better tomorrow from our families and communities. In our country, more than seven million people are HIV-infected; and it is estimated that there are 1 000 new infections every day. Science continues to push the boundaries: progress new HIV treatment and care interventions, movements to control paediatric HIV by reducing maternal-foetal HIV transmission. These have translated into reductions in infant and under-five mortality rates, and increased life expectancy. In the HIV-prevention arena, progress in long-acting antiretrovirals for use in pre-exposure prophylaxis may translate into a powerful prevention intervention. As we advance three HIV vaccine concepts into efficacy studies, we start to think that we may have the kind of tools that have the potential to curb the HIV epidemic globally.*

However, the biggest hurdle to overcome in our fight against HIV is the stigma and discrimination that HIV-infected people face every day of their lives. The true test of beating this epidemic will be whether we as a people have the ability to overcome our prejudices against people living with HIV. While we have at our disposal a series of proven prevention tools to afford us safer sexual choices, it is evident that science and biomedical interventions alone will not help heal our communities and families. Structural factors such as poverty and unemployment, in addition to biological factors such as genital inflammation and viral load, and behavioural factors such as lack of condom use and age-disparate relationships, have combined to make our battle against HIV all the more challenging. If we are to grow the momentum of our battle strategy against HIV, then we must not define people by their living with HIV; but rather, by the lives they fulfil.

Professor Glenda E. Gray, President of the Medical Research Council.

In 2017, it is very encouraging to see expansion of life-saving antiretrovirals *to 21 million individuals worldwide; however, in order to get the full impact of this treatment expansion, we also need to ensure that all 21 million stay on their treatment and become virally suppressed. Sadly, we are not doing well in tuberculosis and without a doubt more emphasis is needed worldwide on improving primary prevention of both HIV and tuberculosis. This will require that we also address structural determinants of universal health: a much harder challenge to meet.*

Professor Linda-Gail Bekker, president of the International AIDS Society & Deputy Director and CEO of the Desmond Tutu HIV Foundation at the University of Cape Town.

The world has made great strides in tackling HIV/AIDS, *but we are in danger of coming to a standstill. Progress has slowed, for a variety of reasons; but a major roadblock is our failure to listen to young people. The largest-ever generation of adolescents in sub-Saharan Africa is at risk of HIV – in 2015, nearly 7 500 young women aged 15 to 24 years acquired the infection each week. Stigma, poor education, and services that are out of touch. We must understand what young people are going through, and react quickly and effectively, if we are to end HIV/AIDS.*

Professor Peter Piot, Director of the London School of Hygiene & Tropical Medicine and former Executive Director of UNAIDS.

→

South Africa has the largest HIV treatment programme in the world *with 4.2-million patients on treatment. This has been achieved through a combination of factors including high levels of activism by civil society formations, political leadership from Minister Aaron Motsoaledi, funding from national Treasury in the form of a conditional grant, training of nurses to initiate patients on first line treatment (NIMART) and support from development partners. However with an estimated 270 000 new HIV infections in 2016 as well as 7.1-million living with HIV and AIDS, it is clear that we have much more to do in both preventing new HIV infections as well as reaching the 90-90-90 targets by 2020. The recently launched Global HIV Prevention Coalition's HIV Prevention Roadmap proposes a target of no more than 88 000 new HIV infections by 2020. In addition, reaching the 90-90-90 targets means that we should have 6.2-million patients on ART by 2020 as well. To meet these targets we will require that all stakeholders fully commit to them, find additional resources as well as work collaboratively. It will also require changes to how we provide services to reach the treatment targets and how we support patients to ensure high levels of viral suppression. We also need to more rapidly decrease new HIV infections by being more creative and fully implementing combination prevention strategies. Our strategies must include dealing decisively with the TB epidemic as well – preventing new TB infections, finding those that have TB and successfully treating them. We have the political will, the motivation, and the means to reach epidemic control by 2020!*

Dr Yogan Pillay, Deputy Director General, South Africa, National Department of Health

Thanks to anti-retrovirals, *AIDS is no longer an inevitably fatal condition, but a chronic, manageable one; rates of infant transmission have been reduced to about 1.5%; and their impact on prevention – directly through viral suppression of infected persons, or through prophylactic use by infected persons – is starting to emerge. Though with nearly 20 million people still to be initiated on treatment globally, a million deaths, and 1.8 million new infections still continuing to occur, we can hardly claim to have turned the corner or the tide! We do have sufficient knowledge to achieve epidemic control, however in sub-Saharan Africa, the HIV and TB epidemics are closely intertwined; failure to integrate HIV and TB services is resulting in continued high mortality rates – as are stigma and discrimination, through creating a barrier to accessing services.*

Stigma remains a major barrier to access to services. We need to partner with infected and affected communities much earlier, and across all stages of developing, evaluating and implementing new interventions.

Getting to this point has required a lot of teamwork, political commitment, global solidarity and innovation – and the next phase is going to be a lot more challenging. But can we afford to reverse the gains made to date?

Professor Quarraisha Abdool Karim is the Associate Scientific Director of CAPRISA in South Africa.

The political momentum for the fight against TB *is now garnering the same type of global attention that HIV achieved in 2000, when the UN General Assembly hosted a Special Session on AIDS, the Global Fund was created, and investments shifted from the millions to the billions. It's not before time.*

Still lagging behind is any serious attention being paid to the plight of women and girls. In fact, things are going into reverse: in January 2017, US President Trump used his first days in the White House to expand the Global Gag Rule to all $8.8 billion allocated to US global health – including funds dedicated to HIV and TB. This is likely to have a devastating impact on the lives of girls and women, especially girls and women impacted by these two diseases. NGOs registered outside the US can no longer provide information or advice about safe abortion, even with their own or other people's funds, if they want to retain funding flows from the US.

All of the hard work done so far to address the human rights of girls and women, and to break through silos, has been endangered. Many HIV programmes have worked hard to address the needs and rights of the women and girls they serve, so that they can access the full spectrum of sexual and reproductive health services alongside their HIV and TB services. Given the heavy reliance of HIV and TB programmes on US funding, catastrophic impacts are predicted that will be counted in the lives and well-being of women, girls and their communities.

Brave politicians – initially from the Netherlands and other European countries, and now from Canada, Afghanistan and a range of African countries – have mobilised. Around the world, thousands of individuals and organisations are standing together under the banner of SheDecides to fight for a 'new normal', in which every girl, every woman, everywhere decides for herself what to do with her body, her life and her future. And you can join them, by signing the manifesto at www.shedecides.com.

Robin Gorna co-leads SheDecides.

The state of the intertwined, global HIV and TB response *is characterised by two signature themes. In the first instance, we have a global community unified in strategic intent to achieve epidemic(s) control, as encapsulated by the UNAIDS 90-90-90 strategy. This unified focus needs to be bolstered even further, as the impact of a successful 90-90-90 strategy will be healthy, HIV positive persons living long, productive lives, while transmitting the virus at far lower rates.*

The second signature theme relates to generalised insecurities globally, and the emerging dominance of more conservative, inward-looking views among donors. This directly affects the HIV/TB programmes that support the poorest and most marginalised of communities. Efforts should be amplified towards lobbying wealthy countries to increase donor support to developing countries, while developing countries should find greater internal resources to support the same.

HIV/TB epidemic control requires long-term, global, sustainable support by – and for – all.

Dr Tim Tucker is CEO of SEAD Consulting and specialist Clinical Virologist

RELATED STORIES:

+ *Pages 10-13 looks at the imapct of PEPFAR 2017 on one orphanage in South Africa.*
+ *Pages 47- 53: Spotlight on TB*

South Africans showed up in their thousands for a day of national action on 7 April 2017 organised by the Save South Africa coalition. Pictured here are protesters outside the South African parliament, one sporting a placard showing the face of a horned President Jacob Zuma and that of his friend Atul Gupta, member of the infamous Gupta family, who is strongly linked to state capture.

Photo: Karien van der Westhuizen

STATE CAPTURE

State capture threatens the right to health

Mark Heywood, SECTION27

> *"In a sector that is scarce and expensive to begin with, corruption can mean the difference between life and death." – Viva Dadwal, Deputy Editor of Globalisation and Health*
>
> *"Making corruption a research subject and a responsibility of health systems researchers in South Africa and elsewhere allows us to name the problem, measure it, and develop and test ideas about how to address it. Such research also allows the global community of health system researchers to contribute towards improved efficiency, effectiveness and social accountability of health systems." – L Rispel et al, 'Exporting corruption in the South African health sector', Health Policy and Planning, 2015, 1–11*

In 2017, a debate raged at the Treatment Action Campaign's (TAC) National Congress about how to respond to corruption across the country. As the levels of scandal and shock around President Jacob Zuma's behaviour have risen, TAC's allies have often called on it to take to the streets and join organisations such as the Save South Africa campaign that are calling for Zuma to step down.

However, within TAC, some activists have asked: 'What does health have to do with party politics?' They argue that TAC should stick to its mission – the right to health – and avoid being caught in a morass of political mudslinging. There is a level of truth in this argument; however, the very birth of organisations such as TAC was in response to a failing political strategy, government and healthcare service, responsible for the deaths of millions of people when they refused to provide adequate treatment for patients with HIV.

Our struggle for the right to health has always been political, and will always remain political. Everywhere in the world, the quality of health has everything to do with politics. South Africa is no exception.

Under apartheid, the majority of the population were denied access to quality health services. When apartheid ended in 1994 there were gross inequalities in health outcomes. That is why "access to health care services" was included as a right for "everyone" in our Constitution.

Today, the Constitution is our supreme law. But South Africa's Constitution started its life as a political agreement between parties to mark the dawn of democracy. The Constitution is like a finely woven tapestry; it has many threads and many strands. Each one weaves in and out of another. Looked at from afar, they compose a picture that promises everyone in our country equality, dignity and social justice.

However, very few of the threads can exist independently. The right of access to healthcare services, for example, cannot be realised in a silo. It is dependent in many ways on good governance, accountability, and a government →

The very birth of organisations such as TAC was in response to a failing political strategy, government and healthcare service, responsible for the deaths of millions of people when they refused to provide adequate treatment for patients with HIV.

that is diligent in the performance of public functions. These too are parts of the Constitution. For example, Section 195 of the Constitution says that:

> *"Public administration must be governed by the democratic values and principles enshrined in the Constitution, including the following principles:*
> *a. A high standard of professional ethics must be promoted and maintained.*
> *b. Efficient, economic and effective use of resources must be promoted.*
> *c. Public administration must be development-oriented.*
> *d. Services must be provided impartially, fairly, equitably and without bias.*
> *e. People's needs must be responded to, and the public must be encouraged to participate in policy-making.*
> *f. Public administration must be accountable.*
> *g. Transparency must be fostered by providing the public with timely, accessible and accurate information."*

Section 237 says:

> *"All constitutional obligations must be performed diligently and without delay."*

What this means is that where government is bad, access to health services fails. Without access to healthcare services, people's health will deteriorate.

Very few people now deny that we have a very bad government. In the last two years our country has been in the throes of a crisis caused by what is now known as 'state capture'. Theft by people such as the Gupta family has been facilitated by President Zuma and other Cabinet members.

Unfortunately, the story of state capture has been told in a one-sided way. Most of the focus has been on institutions such as SARS, Eskom, SAA, PRASA and now the Treasury. But with the combined budget of the national and provincial health departments now around R190 billion per year, the health system also offers rich pickings for those intent on theft. In this context, the capture of big health tenders, ambulances and institutions such as hospitals is also common.

How corruption manifests itself in the healthcare system

Corruption is a serious threat to the majority of the population who rely on public hospitals and clinics. Not only does it make it difficult for them to receive proper treatment when they are vulnerable and cannot pay a bribe, but when funds, medicines and equipment are stolen or misused by officials, it can have devastating effects on communities at large.

TYPE OF CORRUPTION	EXAMPLES
Informal payments	Unofficial payments given to healthcare providers which are more than the official cost of a service, or for services that are supposed to be free
Selling of government posts	A senior official in a position of power demands a payment from government agents to secure or keep their positions
Moonlighting	Healthcare professionals abusing leave policies or conducting their private practice during work hours
Bribes	Money or something of value promised or given in exchange for an official action
Procurement corruption	Includes many types of abuse, such as bribes, kickbacks, fraudulent invoicing, collusion among suppliers, failure to audit performance on contracts, etc.
Theft or misuse of property	Theft or unlawful use of property such as medicines, equipment or vehicles for personal use, for use in a private medical practice, or for resale or renting out
Fraud	Includes false invoicing, 'ghost' patients or services (billing for patients who do not actually exist or services that were not rendered), and diversion of funds into private bank accounts
Embezzlement of funds	Officials, healthcare providers or other individuals stealing or deliberately diverting national funds allocated for healthcare services
Nepotism	Employment opportunities are given to friends and family members based on personal connections instead of merit
Improper healthcare accreditation	Individuals or groups approve a healthcare professional's qualifications due to personal or political connections with the professional or the receipt of a bribe
Inappropriate healthcare facility certification	Officials provide unwarranted certification to a healthcare facility, due to personal or political connections with the facility operators or the receipt of a bribe
Inappropriate healthcare training facility certification	Officials provide unwarranted certification to a healthcare training facility, due to personal or political connections with the college owners or the receipt of a bribe

Source: Corruption Watch/SECTION27

However, while we can point to specific instances of corruption in the health system (as I do below), there has not been enough investigation of the overall levels of corruption – or its impact. But it is large. In 2011, for example, SECTION27 and Corruption Watch commissioned research (*Corruption in the South African Health Sector*, Benguela) that concluded that up to R20 billion a year was being lost to corruption in the public and private health sector. It warned that: "If the current corruption risk remains and is not appropriately addressed, it will inflate the cost of health care, limit access to services, and negatively impact on the quality of care."

More recently, research by Laetitia Rispel and others recorded that the majority of people they interviewed "were of the opinion that corruption is pervasive, particularly in the public health sector. For example, commenting on corruption in the public sector, respondents note that it is 'rampant' (Private Hospital Manager) and has 'reached uncontrollable levels' (Provincial Department of Health Director)."

Rispel et al attempt to quantify the cost of corruption in health by studying levels of "irregular expenditure" that are recorded in reports of the Auditor General. Irregular expenditure is money that is spent without proper authorisation and outside of the legal framework. It is not automatically corrupt – but a very large part of it is. They found, for example, that in four financial years between 2009 and 2013, the total amount of irregular expenditure within provincial health departments was over R24 billion.

This is a huge amount of money! It is the equivalent of the annual budget for the HIV conditional grant, or twice the amount currently spent on Emergency Medical Services (which we know to be woefully inadequate).

Total amount assessed by Auditor-general as irregular expenditure, 2009/10-2012/13, by province. Nominal ZAR '000 – with real ZAR '000 December 2012 in brackets.

PROVINCE	2009/2010	2010/2011	2011/2012	2012/2013
Western Cape	**27 168** (30 803)	**119 194** (128 719)	**74 000** (75 665)	**86 700** (83 849)
Mpumalanga	**0** (0)	**15 281** (16 502)	**285 061** (291 473)	**123 100** (119 052)
Eastern Cape	**1 327 628** (1 505 247)	**278 320** (300 562)	**436 000** (445 808)	**304 000** (294 004)
KwaZulu-Natal	**637 725** (723 044)	**562 329** (607 267)	**2 038 000** (2 083 845)	**2 719 200** (2 629 787)
Limpopo	**159** (180)	**401 477** (433 560)	**625 600** (639 673)	**571 200** (552 418)
Free State	**273 615** (310 221)	**318 543** (343 999)	**45 300** (46 319)	**143 700** (138 975)
Gauteng	**455 643** (516 602)	**2 246 121** (2 425 617)	**1 100 000** (1 124 744)	**1 524 200** (1 474 081)
Northern Cape	**100 872** (114 367)	**1 074 860** (1 160 756)	**942 000** (963 190)	**1 064 500** (1 029 497)
North West	**513 759** (582 493)	**949 487** (1 025 364)	**1 726 000** (1 764 826)	**971 300** (939 362)
TOTAL	**3 336 569** (3 782 958)	**5 965 613** (6 442 347)	**7 271 961** (7 435 543)	**7 507 900** (7 261 025)

Base 100 = December 2012. Source: Auditor-Genreal of South Africa, 2014.

When such massive amounts are misspent and stolen, there is bound to be an impact on the availability and the quality of care in the health system. Much of this corruption was intensified after Zuma became president; and in the dying days of his rule, the rot within the health system has become increasingly evident. Corruption is no longer the hidden hand passing brown envelopes under the table. It unashamedly smirks at us while its wickedness creeps into all corners of the public and private sector, infecting many with the desire to plunder the public purse for self-enrichment. →

Below are some examples of corruption that have been confronted by SECTION27 and TAC.

a. Gauteng Health Department: a rogue unit

The Gauteng Health Department is possibly one of the most corrupt provincial health departments in the country. Its irregular expenditure for the period of 2010/2011 to 2016/2017 was calculated by the Auditor General to be a massive R6.9-billion.

The rot appears to have started about ten years ago, with then-MEC for Health Brian Hlongwa. Hlongwa is facing charges of corruption. Due to the capture and collapse of our criminal justice system, Hlongwa has not yet faced the consequences of his corrupt behaviour. Hlongwa is currently facing charges of corruption and money laundering relating to two tenders worth R1.4-billion. It is alleged that in 2007, Hlongwa fraudulently rigged two tenders so that they could be awarded to 3P Consulting and Boaki Consortium, and that he received various kickbacks in return. 3P was initially paid R120 million to establish a project management unit for the department, but they ended up earning R392 million by the time their contract was cancelled in 2009. Boaki was awarded a tender worth R1.2 billion to set up a health information and health records system. By the time their contract was cancelled in 2008, they had been paid R400 million, but no infrastructure had been set up.

In 2010, the Special Investigating Unit (SIU) was given a mandate to investigate these matters by a Presidential Proclamation. It has been seven years, and still no-one has been brought to book. Hlongwa is currently serving as the ANC Chief Whip in the Gauteng Legislature, and has continued to operate with impunity. He recently noted: "I was once a minister, an MEC of health from 2006 to 2009 in Gauteng. There is a cloud hanging over my head. I am supposed to be somebody who is corrupt as well. It has been nine years. But there is no case." Looking at the current state of affairs and the political puppets in charge of the National Prosecuting Authority, it seems unlikely that Hlongwa will be brought to justice for crippling the GDoH.

In 2009 Hlongwa was replaced by disgraced MEC Qedani Mahlangu. Between the two of them they have managed to bankrupt the GDoH.

As a result the price of corruption is being felt in collapsing services; community health workers go unpaid because of corruption; babies die or are disabled because there are not enough midwives and nurses; people acquire TB and MDR-TB because there are no systems for infection control. As we saw recently, hospitals treat dead bodies like the carcasses of animals.

The worst example of the results of corruption is the Life Esidimeni disaster, which caused the death of at least 143 mental-health patients. The arbitration currently under way aims to find the truth. At this point, the real reasons patients were moved out of Life Esidimeni and dumped into unregistered 'NGOs' where most of them died must still come out. But some of the evidence seems to suggest that senior officials such as Dr Makgabo Manamela, the head of mental-health services, may have had corrupt relationships with some of the 'NGOs' to which they sent patients.

These 'NGOs' profited from patients the GDoH sold them to care for, several of them making hundreds of thousands of rands. There is also some evidence that they benefited from the patients' disability grants and life insurance.

But Life Esidimeni is not just about a few corrupt individuals. The Gauteng healthcare system has been corrupted. Instead of being managed as a system for health care, it is seen by politicians and public servants as a get-rich-quick scheme. And the most senior officials in government – like president Zuma – turn a blind eye to this, because the individuals involved are usually part of a political faction whose support they depend upon.

One significant casualty of corruption in the GDoH is the National Health Laboratory Services (NHLS). The NHLS can be thought of as being the arteries of the public-health system, and particularly of the response to HIV and TB. It is like the Eskom of health. Controlling AIDS and TB is totally dependent on laboratory tests for HIV such as CD4 count and viral load, and on technologies such as GeneExpert. However, the GDoH owes over R2.5 billion to the NHLS… but says it can't afford to pay its bill.

To make matters worse, people who work in the NHLS allege that there is rampant corruption and mismanagement by senior officials. In the latest financial year, the NHLS incurred nearly R1 billion in irregular expenditure. If the NHLS collapses as a result of its burden of debt and corruption, large parts of the health system will go under with it.

The rot [in the Gauteng Department of Health] appears to have started about ten years ago, with then-MEC for Health Brian Hlongwa. Hlongwa is facing charges of corruption.

b. Corruption in the Free State Department of Health

But Gauteng is not the only provincial health system where thieves rule. For several years, TAC and SECTION27 have tried to spotlight corruption in the Free State Department of Health. Dr Benny Malakoane, who was the MEC for health between March 2013 and October 2016, had already learnt his thieving ways by the time he became MEC. He is on trial for charges of corruption related to his past employment, but every time he is due in court he and his accused seem able to engineer a postponement.

In 2015 a whistle-blower contacted SECTION27 to tell us that Benny Malakoane had introduced a programme for unproven stem-cell treatment of geriatric patients at two hospitals in Bloemfontein. The programme was costing the Free State DoH R3 million a month, and would run for three years. It was alleged that Malakoane had a direct relationship with the company that was providing the 'service'. Fortunately, on the basis of the information provided by the whistle-blower SECTION27 was able to inform the Director General in the DoH, who quickly investigated and then closed the programme down. Tens of millions of rands were saved from theft.

c. Theft of medicines

As we know, South Africa now has the biggest anti-retroviral (ARV) programme in the world. Billions of rands are spent on medicines every year. This is also an area vulnerable to corruption. For example, when the issue of major stock-outs first became a concern in 2013, one of the reasons was rampant theft at provincial medicine depots such as that in Umtata. A report produced by TAC and MSF at the time noted that at any one time, the Umtata depot would have medicines in stock worth up to R40 million – and noted how much of this was at risk of being stolen. In recent years – in part because of TAC and SECTION27's activism, and the monitoring of the Stop StockOuts Project (SSP) – the management of provincial medicine depots has improved, reducing the risk of corruption.

Conclusion: AIDS activists must be anti-corruption and social justice activists!

The examples I have given above are reasons that AIDS activists must also be political and social justice activists.

Politicians are the gatekeepers of the resources allocated to and spent on healthcare services. When their greed supersedes the needs of the people, and results in the crippling of our health institutions – and in many instances, leads to the deaths of our most vulnerable – we must then admit that we are indeed a sick society. The president might not have had direct involvement in cases such as Life Esidemeni and the crumbling of the NHLS; but the system of thievery that festered under his leadership allows for a Qedani Mahlangu, and makes the call for his removal all the stronger.

The fact that access to healthcare services is a constitutional right does not mean we should think that health is automatically protected. It is contested by the everyday behaviour of officials who steal from funds intended to realise that right. If we don't root out corruption in the public-health system, the health system will collapse. According to Rispel and others: "Poor governance and corruption share a reciprocal relationship and negatively impact on the morale of healthcare providers, the majority of whom are committed to service excellence". They go on to say that:

> *"Although legislation seems adequate, initiatives by government to identify and ameliorate vulnerabilities to corruption within the health sector need to be further developed. Proactive mechanisms to detect corruption and the enforcement of negative sanctions against those found guilty of corruption are important interventions to create disincentives for engaging in corrupt activity."*

Unfortunately, it doesn't seem that the national and provincial health departments take corruption seriously, or that it is being seriously investigated by bodies such as the Hawks or the NPA. Their responses are usually reactive to reports by civil society and the media, rather than part of a proactive plan to root out corruption in the health sector. Until there is political commitment to really fighting corruption, civil society will have to fill the gap by exposing and reporting corruption.

On a day-to-day basis this requires strengthening of community oversight through participation in hospital boards and clinic committees. It means organisations that monitor health-service delivery (such as the Stop Stock-outs Project) are vital. Re-establishing bodies such as the Budget, Expenditure and Monitoring Forum (BEMF) is also essential.

Civil society needs to constantly monitor institutions such as SANAC, from where there have been reports of corruption involving civil society leaders. We also need to investigate tenders worth hundreds of millions of rands, such as that given to the controversial company Sadmon for a health communications strategy that is mostly invisible and ineffective.

Finally, on a political level it means that TAC should join forces with those challenging corruption at the highest level, including that of the President and the ruling party.

If state capture and corruption is not investigated and punished, South Africa will end up with a public-health system as broken and dysfunctional as that in other African and Asian countries. That, surely, is something we must do everything we can to avoid.

When [the] greed of politicians supersedes the needs of the people, and results in the crippling of our health institutions – and in many instances, leads to the deaths of our most vulnerable – we must then admit that we are indeed a sick society.

Sporting their blue golf shirts are some of the Koinonia Orphans caregivers who have changed the lives of at least 900 children in 13 villages in Uzimkhulu. From left are Ntombovuyo Langa, Bongekile Dlamini and Gloria Tsezi. In front is Lodiwe Ndzimande.

Photo: Ufrieda Ho

PEPFAR FALLOUT

Funding by faith

Ufrieda Ho, Spotlight

A community caregivers project for rural KwaZulu-Natal AIDS orphans and vulnerable children hangs in the balance as donor money from the United States dries up.

Even for a woman of faith, breaking bad news is never an easy thing to do.

When Sister Krystyna Ciarcińska called a meeting for the 30 caregivers of the Koinoina Orphans Project in rural Umzimkhulu, KwaZulu-Natal at the end of winter this year, she did so with a heavy heart.

"I was so sad and I didn't know what I was going to say to them," she says, remembering that day. In her hand was the letter from the South African Catholics Bishops Conferences (SACBC) notifying the Lourdes Mission, where Sr Krystyna is a consecrated sister of the Koinonia John the Baptist community, that funding for the two-year-old Koinonia Orphans Project she headed up, would run out by the end of September.

"Sometimes when we call special meetings it's because we have been given unexpected donations of blankets, mattresses or something, so the caregivers were very excited. But instead I had bad news to tell them; it was terrible," she says.

That official funding has dried up and it has been a blow. But the Lourdes Mission has fought to continue with the project even though for the past few months paying the R35 000 a month bill it costs to run the project has never been a certainty

"Prayers and providence," says the irrepressible Sr Krystyna with a smile, at how donations have materialised. Still, she's only too aware that the long-term sustainability of the project is in jeopardy.

The Koinonia Orphans Project has over the last two years become a vital lifeline for over 900 children registered in the project and their families from the 13 villages that surround the mission station. The 30 caregivers who receive a stipend for their service also rely heavily on this source of income.

The project that started in October 2015 focuses on supporting children in vulnerable households, many are AIDS orphans. It's part of the Catholic Church's response to HIV/ Aids that was officially started in the country in 2000.

Withdrawal of PEPFAR funds

The SACBC has been a beneficiary of the United States' Pepfar (President's Emergency Plan for Aids Relief) funding since the fund came into being officially in 2004. The shift in foreign policy under the Trump administration has however, sparked concern for critical long-term financial support from Pepfar.

According to Mrudula Smithson, director of the SACBC AIDS Office, Pepfar funding to the SACBC has been reduced by around half for the next financial year. While Smithson says they don't disclose the actual amounts, she says their projects have been hit badly.

"We receive three streams of Pepfar funding for our projects that all focus on orphaned and vulnerable children – all three have been severely affected while our target of the number of children we want to reach has increased significantly," she says.

Smithson adds that the SACBC Aids Office programmes currently reaches 45 000 children. "We are very concerned that the small projects around the country especially now have to find their own way to fund their programmes or they'll have to shut them down," she says.

At this point, Pepfar will continue to fund projects in South Africa till September next year. In May, the US Embassy in Pretoria announced that Pepfar would support South Africa's HIV/AIDS and TB programmes till September next year and would support the National Strategic Plan (NSP)'s 2017-2022 programmes for HIV, TB and Sexually Transmitted Infections. An additional U$51-million in funding was approved to support South Africa's voluntary male medical circumcision programme. Since 2004, Pepfar has invested over U$5.6-billion in South Africa.

A million realities away from decisions made in boardrooms in capital cities, Koinonia Orphans Project caregivers must still get on with visiting families under their care.

Giving care

With basic training in nutrition, hygiene and counselling, caregivers help make sure people adhere to their medicine regimes and have food to eat, often they share from their own meagre provisions. They cook and clean, fix homesteads, and help plant food gardens. They also help register children for birth →

A million realities away from decisions made in boardrooms in capital cities, Koinonia Orphans Project caregivers must still get on with visiting families under their care.

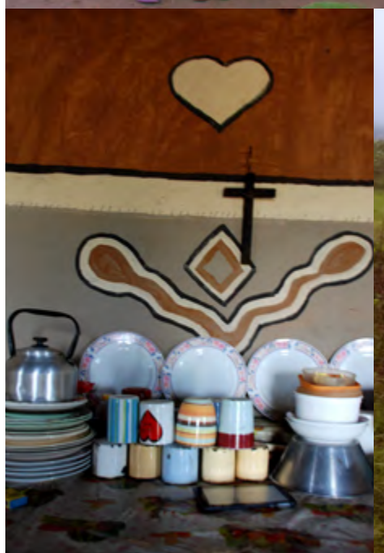
TOP LEFT: The Lourdes Mission has suffered from neglect, abandon and fire for over one hundred years. Goats graze where the remains of the convent that the Koinonia John the Baptist community hold to rebuild.

ABOVE: The home headed by Christina Mtolo (far right), her daughter Gloria Mbhele (far left) and with them Gloria's children Anelisiwe Mbhele, their friend Thembalethu Tshabalala, and Gloria's other child Senelweko. They are one of the families that are part of Koinonia Orphans Project.

BELOW: When rain sets in in the hills of Umzimkhulu it brings with it cold and winds that make tough lives even tougher.

BELOW LEFT: Wall decoration inside a rondavel.

LEFT: Granny Tryphina Mkalane has lost her daughter and another is in Durban looking for work. It means she has to look after five of her seven grandchildren.



Photos: Ufrieda Ho

certificates and identity documents. They do school monitoring, help with homework and ensure that children have school uniforms, without which they're not allowed to attend school.

Another prong of the Koinonia Orphans Project has been twice yearly voluntary HIV/AIDS testing and counselling days targeted at children but also reaching adults who live in communities surrounding the Lourdes Mission.

In their last testing campaign held in August they were able to test 400 people, working in collaboration with local clinics that provided the pin-prick test kits.

"Knowing their status early is important so that they can start treatment early," says Gloria Tsezi, one of the Koinonia caregivers in the village of Moyeni.

Tsezi visit homes where the burdens facing families is heavy. At the home of Busisiwe Khambula and her three children, Tsezi looks on as Khambula cradles in her lap the head of her eldest of three children, Olwethu (18). He is severely disabled and often suffers from uncontrollable fits.

"Sometimes the clinic tells me there are no medicines for his fits, then I have to go to Rietvlei Hospital. Sometimes I just lie him down flat and wait till the fit is finished – it hurts my heart too much," Khambula says. Transport to get to the hospital costs her R200.

Tsezi and Khambula also tell of Khambula's allegedly abusive relationship with the mostly absent father of her children. Abuse is another load that women in this remote district of KZN must carry.

Tsezi says: "He threw away all her pots and burnt all the children's documents so I had to help get new identity documents for the children.

"I come to look after Olwethu and the two smaller children, Jabulile and Simthanda, when Busisiwe must go out. I give Olwethu soft porridge and milk, it's the only thing he can eat – he likes it," she says, proudly wearing the sky-blue Koinonia golf shirts that have become the uniform of the projects' caregivers.

A difficult life

A few villages away in Riverside, a mother tells of her trials of living with HIV and the devastation of some years ago when she found out that one of her children, an 11-year-old girl, is also HIV positive. The child has also suffered from TB, she says.

They have a vegetable garden but sometimes there isn't enough food for a square meal – essential for those taking ARVs. Riverside was also without water for nine months this year.

In another village Tryphina Mkalane is grieving for her daughter who died just months ago. It's added two more grandchildren under her care, bringing to five the number of young ones who live in her rondavel.

One of the children turns 18 soon. Mkalane worries she will not find a paying job. At the same time it will mean she'll lose a social grant that goes towards paying for groceries, transport and school supplies.

"One of my other daughters is in Durban. She's been trying to find a job for over a year now. We send her the grant money so she can pay rent in Durban," says Mkalane, speaking through her caregiver, Lucinda Dlamini.

For Sr Krystyna, who grew up in Poland and arrived in South Africa from Spain first in 2013 then permanently since April 2014, helping to lighten people's challenges bought on by the collision of multiple miseries has become part of her life's work.

Every sad story breaks her heart, but not her faith. Her childhood fascination with Africa has turned into the place she now calls home. In return the community has embraced her as their own, there are even little girls bearing her name – spelt the Polish way – the mothers and the nun say with a laugh.

It was in 2010 that the arduous process of rebuilding the Lourdes Mission and their cathedral first started under invitation by the local bishop to Father Michal Wojciechowski, who now heads the Koinonia John the Baptist community in Lourdes.

The mission station and cathedral date back to 1895. They were built by Trappist monks but had been given over to neglect and abandon for decades. Brick by brick the community has worked to rebuild the twin-towered cathedral and the living quarters for the handful of nuns and brothers who keep the mission alive.

There's still a mountain of work to be done, like restoring a burnt out convent and an adjoining boarding school.

Every day there are new needs that present at the Lourdes Mission's doors. The sisters, brothers and Father Michal open their arms to it all: a woman and her children who have gone three days without a meal; the shattering news of a teenage suicide; someone needing help with homework or just seeking out comfort and a prayer – and of course, the on-going question of how to fund the Koinonia Orphans Project for the the long-term.

But the cathedral is a beacon of joy and spiritual light. It's packed to capacity for Mass each Sunday, the mission's food garden and orchards now thrive as a symbol of new hope. Funding is sorely needed here; faith in action though, grows with abundance.

"Sometimes the clinic tells me there are no medicines for his fits, then I have to go to Rietvlei Hospital. Sometimes I just lie him down flat and wait till the fit is finished – it hurts my heart too much," Khambula says. Transport to get to the hospital costs her R200.

ABOVE: 95-year old Alexsia Njilo can barely look after herself and says here two teenage grandsons don't give her much assistance.

BELOW: Bertha Mia is co-ordinator of the Koinonia Orphans caregivers, with her is Thembile Dzanibe, one of the youngest caregivers in the project.

Photos: Ufrieda Ho

PEPFAR FALLOUT

Burden of the generations

Ufrieda Ho, Spotlight

When the rain sweeps in over the hills of Umzimkhulu and the winds follow, the rolling hills turn to mud and muck. Mist and chill wrap around rondavels with little forgiveness.

Gogo Alexsia Njilo (95) calls this remote part of southern KwaZulu-Natal home. On a soggy, cold afternoon, the nonagenarian tends a steel teapot warmed on burning firewood in the centre of her rondavel. In-between she shoos away chickens pecking on the dung-mud floor, also seeking the mercy of warmth. Njilo lives with two teenage grandsons here that she mumbles are no good and no help to her. They come and go as they please, she says.

"I won't cook tonight because they will just eat all my food," she says in Zulu, I will drink tea for my dinner, she says.

So much adds to Njilo's hardships: maladies of old age; few opportunities or hope for young people in this remote village and little infrastructure and resources to make life easier for a family living in poverty in the Harry Gwala district. The district has been in the news of late for political killings, cases of corruption and municipal mismanagement, also lack of infrastructure and pressing needs for basic services.

Njilo's is one of the vulnerable households under the care of the Koinonia Orphans Project, run by the small community of consecrated sisters and brothers from the Catholic Church's Koinonia John the Baptist community, based at the Lourdes Mission in a neighbouring village.

The 95-year-old's Koinonia caregiver is the newest and youngest in the project: 19-year-old Thembile Dzanibe, who joined them in the middle of November.

Dzanibe finished her matric in 2016 and had been looking for work ever since.

"Many young people are in the same situation as me. Here in the rural areas there are no jobs or opportunities, nobody has work, they just have to sit at home. I applied for bursaries to study but I wasn't accepted," she says.

Added to this she says there's a growing drug problem and a deep-rooted crisis of alcohol abuse that often leads to violence and criminality. Teenage pregnancy is also common and HIV/AIDS continue to ravage the community.

As a born-free, Dzanibe had hopes of studying to become a teacher. She says: "Actually my dream is to open a crèche, I love children."

But both dreams have stalled.

"I'm happy to be a caregiver this year, I think I will be able to look after Gogo and the two boys, even though I don't know if they'll listen to me," she says, sitting inside Njilo's hut.

Gogo's face does light up to greet her young caregiver but she's also lost to tiredness and her own thoughts.

For Bertha Mia, the co-ordinator of the Koinonia caregivers, the role that Dzanibe has committed to is a big one.

"You need patience to do this job; you also need to treat every person with dignity. You have to work hard and be honest," says Mia.

Dzanibe nods as Mia passes on this advice.

Community caregivers take on an intimate, sometimes almost impossible task. They're a pillar that props up the most vulnerable in society, yet as in the case of the Koinonia Orphans Project they're also first to fall when funding dries up.

So much adds to Njilo's hardships: maladies of old age; few opportunities or hope for young people in this remote village and little infrastructure and resources to make life easier for a family living in poverty in the Harry Gwala district.

Free State MEC for Health, Butana Khompela.

Photos: www.bloemfonteincourant.co.za

***Spotlight* is profiling all nine of South Africa's provincial Health MECs. We continue with a profile of the MEC for Health in the Free State, Butana Khompela.**

SPOTLIGHT ON MECS FOR HEALTH: FREE STATE

Heading for the rocks?

Ufrieda Ho, Spotlight

One year into his tenure as MEC for Health in the Free State, Butana Khompela is still to exorcise the ghosts that have made the province one of the worst-performing when it comes to health.

Khompela came into his role in October 2016 – replacing Dr Benny Malakoane, who was moved to the Department of Economic, Small Business Development, Tourism and Environmental Affairs. Malakoane's exit from the Department of Health was met with relief – pure celebration, even – from activists and many Free State locals, desperate for improvement in the state health services.

Their elation at seeing the back of Malakoane was because his track record in the department was woeful at best. He was routinely and widely called out for abuse of power, and for a leadership and management style that smacked of bullying and arrogance. So bad was Malakoane (who served as MEC even while he faced charges of fraud, corruption and money laundering) that the Treatment Action Campaign (TAC) embarked on the intensive, two-year-long #FireBenny campaign. Finally, Malakoane was removed (albeit only sideways) and sent off with a farcical pat on the back from ANC leadership.

It's to these choppy waters that Khompela has been brought to steady the ship of an almost wrecked department, which remains under provincial administration. Its one-time top academic hospital, the Universitas Academic Hospital in Bloemfontein, tumbled to the bottom of the pile in the country in the October 2016 findings of the Office of Health Standards Compliance (OHSC).

TAC notes also that a large number of vacancies remain unfilled. The information for appointments and vacancies on the Provincial Department of Health's website simply shows 'n/a' under 'current financial year information'. Just looking at the available data from the 2015/2016 financial year, however, reveals that there were 20 952 posts approved and 17 810 filled, leaving a shortfall of 3 142 vacancies – about 15% of posts – even in the previous year.

Another lingering issue is the reinstatement of Community Health Workers (CHWs). There remains a black mark against the department for its shameful handling of the protests by CHWs that led to the BopheloHouse94 court case last year, eventually ending with a court ruling in favour of the 94 CHWs.

Also ongoing is the issue of the use of the Buthelezi ambulances and emergency medical services in the Free State, despite the tender granted to the company being irregular, and the services being slammed for their dysfunctionality.

For the 2017/2018 year, the Department of Health was assigned R9.77 billion from the provincial budget. The budget only benefited from a small year-on-year increase of 8%.

In his budget address, Khompela said that "corruption is a cancer", and promised to root it out – also, to bring down the staff bill from 65.8% to the 60% national target. He trumpeted successes in the province's HIV programme, despite these efforts falling short of their targets, as well as the acquisition of a helicopter and an additional 12 maternity ambulances for the province.

Delivered in air-conditioned chambers, budget-speech promises don't always match up to on-the-ground realities. TAC district organiser Mary Nyathi says that under Khompela, little has changed. "We still hear cases every day of someone going to the hospital at 2am to be in the queue, and only seeing someone round about 5pm," she reports. "We have clinics where the roofs are leaking; and even where they have done upgrades, there are no doctors in the buildings to see to the patients."

Nyathi routinely hears of scheduled operations being delayed without explanation, and says that while TAC hasn't had reports of ARV stock-outs, there are routine drug shortages. "I want Khompela to come out of his office and come to the people, so he can understand and see for himself how bad the problems are," she says. "It is heartbreaking that things are not changing. For me, in the lower classes of society, I need these hospitals – tomorrow, it could be me."

Her hope is that Khompela will prove to be a better communicator than his predecessor, and that he will demonstrate a willingness to listen and to collaborate. For Thabo Mahlatse, TAC provincial organiser, poor infrastructure and shortage of medicines and personnel continue to be the bane of the people of the Free State. "We want Khompela to show leadership and accountability, and come up with a plan on implementation – not just what they say in speeches," he says. →

Khompela's had a mixed response from others, too. Some consider him an approachable man, and a person who is sensitive to the dire health challenges in the province. He gets a thumbs-up even from his political opponents: the Democratic Alliance, the official opposition in the province.

Mariette Pittaway, DA member of the Provincial Legislature, says that in the past year, she's found him accessible and prepared to help. "I have sometimes had to call him to intervene in very dire cases, and he has always tried to help," says Pittaway. "The saddest part for him is that he has inherited a mess; and every day I receive another desperate case, or another complaint."

But another Bloemfontein NGO that's operated in the HIV/Aids support arena for the past 10 years says Komphela and his team have repeatedly fobbed them off, instead of agreeing to meetings. "There's a lack of communication, and a lack of good faith," says the co-ordinator, who did not want to be named. She adds: "There still seems to be a lot of smoke and mirrors in the Department of Health, and no appreciation of the value of what the NGO sector is doing."

Smoke and mirrors and a desperate need for clarity are features that extend to parts of Komphela's official Facebook bio page, still active despite not having being updated since 2013. The 53-year-old Komphela was born in Kroonstad and grew up in a farming community, one of 11 children. His brother is the celebrity footballer, coach and Lamborghini-loving Steve Komphela. He is married to Cecilia Nombuyiselo, and they have a grown-up son and a teenaged daughter.

According to the information on the page, Butana Khompela became an activist while just a school pupil. His bio data says he was among those detained along with three teachers during the 1976 uprising – if that timeframe is correct, it would mean he was only 10 years old that June.

The bio write-up goes on to say that as a 19-year old in 1984, he took a job as an admin clerk in the Department of Home Affairs, and later became an interpreter at the local court. But by 1990, Khompela had apparently shot up the political ladder. If his own Facebook page is correct, he was mayor of Kroonstad between 1990 and 1992 (two years before the end of apartheid, and when Khompela would have been just 25).

It must be remembered that Kroonstad in those years was gripped by politically motivated assassinations and violent terror, thanks to the Three Million Gang and the Self-Defence Units (SDUs). Khompela's name is absent from the story of this period – and the mayor of Moakeng (Kroonstad) at the time was Caswell Koekoe.

His bio information goes on to add that Khompela represented Kroonstad when the ANC held its first conference in Durban-Westville, after being unbanned in 1990. He also took part in the Codesa talks, it says.

What is clear is that Khompela is an ANC party loyalist. By the time democracy dawned in 1994, he had been made a director in special education in the Department of Education. His Facebook page continues to map out a political career trajectory that includes becoming a member of the Free State Legislature, moving up the ladder to a position in the National Assembly before becoming chairman of the Portfolio Committee on Sport.

After 10 years in this post he was back in the Free State to become a member of the legislature once more, before becoming MEC responsible for Police, Roads and Transport and now MEC for Health.

During his time on the Portfolio Committee for Sport, Komphela was outspoken about transformation, and infamously raised the ire of the South African Council of Churches after he took vicious aim at then-Archbishop Desmond Tutu, calling him "treacherous", and warning him not to confuse transformation with tokenism. He also locked horns with the likes of Moss Mashinini, who headed up SASCOC, and was slated as "slanderous" and "racist" for his take-no-prisoners approach to transformation in sport.

Back then, Komphela earned a reputation for being something of a firebrand and a hothead. Other adjectives linked to the man include 'irascible', 'power-hungry' and 'meddling'. But he was unapologetic, putting his outbursts down to being a man who calls a spade a spade, and someone who made transformation in sport a priority.

Since grabbing headlines for his time serving on the portfolio committee, Komphela's column centimetres have been dominated by his connection to a Robben Island ferry business in which he has ownership. In August 2008 the *Mail and Guardian* reported on Komphela's interest in bidding for a ferry business operating from Cape Town's mainland to Robben Island. It ended in a commercial dispute, said the newspaper, and the vessel involved became a white elephant (not unlike some of the brand-new hospitals in the Free State), stranded in a Cape Town boatyard.

In June this year, *Times Live* reported that the MEC – who is chairman of Meltt, a business consortium – had bought a R60-million vessel to be a "back-up" ferry for tourists. The concern is that Komphela will have an unfair political advantage over other bidders and operators.

But people waiting for surgery, or desperate to be seen by a doctor or to have an equipped ambulance arrive in an emergency, would prefer Komphela to spend more time getting the health department ship-shape, rather than being focused on cashing in on the tourist spend in Cape Town.

* In May this year, numerous requests were made for an interview of any kind with the MEC. His spokesperson and his communications team responded, saying that they would try to make it happen. Despite much to-ing and fro-ing, with emails, calls and messages, it didn't. Email questions were also sent to spokesperson Mondli Mvambi – among them, questions asking for clarity on the information on the MEC's Facebook page, as well details of his plan of action for the Free State Health Department. No response has been received.

What is clear is that Khompela is an ANC party loyalist. By the time democracy dawned in 1994, he had been made a director in special education in the Department of Education.

FREE STATE HEALTH

Broken bones, broken state

Anso Thom, Spotlight

Patients with broken legs, arms and other serious orthopaedic conditions are being sent home in the Free State because the buckling health system is simply unable to cope with the numbers. Health workers are told there is no money to bring in outside help to reduce the waiting lists.

A week ago, when a team of outside health workers were paid to work a weekend at Bloemfontein's Pelonomi Hospital in an attempt to reduce the waiting list, at least 40 patients were sent home because there was simply no capacity to get to them.

"Imagine this, for six weeks these patients have been lying in hospital beds with well-meaning doctors assuring them that their surgery was imminent, only to be told that you will no longer be operated on and that this means you bones will no re-attach properly or that your ankle will remain partially dislocated," said a health worker, who asked to remain anonymous for fear of reprisals.

What was more disturbing for the health workers who spoke to *Spotlight* was the fact that last year there was millions to run a dodgy, illegal stem cell practice in the Pelonomi orthopaedics department, but there was no money to bring in extra health workers to reduce the waiting list.

"It simply cannot continue like this, patients wait for 40 days for simple, straightforward treatment for fractures. Their lives are destroyed, it is an untenable situation," said a doctor.

The Regenesis scandal

Spotlight reported towards the end of last year that illegal stem cell experimental treatment was being provided at Pelonomi Hospital, a state hospital in Bloemfontein. The issue was also investigated by *Carte Blanche* who produced an insert.

Shortly after SECTION27 and the Treatment Action Campaign brought details of the Regenesis project to the attention of the national Director-General of Health Precious Matsoso, the Medicines Control Council (MCC) suspended the unlawful stem cell experimentation at Pelonomi.

At the same time the Free State Department of Health cancelled its contract with the stem cell company, ReGenesis Biotechnologies following a list of questions sent by Spotlight in connection with the involvement of controversial Health MEC Dr Benny Malakoane. Before the expose, the Free State department of Health was set to spend tens of millions of Rands on unproven and potentially dangerous stem cell therapies for the treatment of musculoskeletal diseases in its orthopaedic knee patients at two hospitals. The treatment was run by a private company called ReGenesis Biotechnologies and has started on June 1, 2016.

A service level contract (seen by *Spotlight*) between the Free State Department of Health and ReGenesis Biotechnologies indicated that the service would be provided in Pelonomi hospital in Bloemfontein and Boitumelo hospital in Kroonstad. The department would pay R30 000 per client, with a guaranteed supply of one thousand patients per year. This adds up to R30-million per year and R90-million over the three years of the contract. →

"It simply cannot continue like this, patients wait for 40 days for simple, straightforward treatment for fractures. Their lives are destroyed, it is an untenable situation," said a doctor.

ABOVE: An overcrowded watiting area at Pelonomi Hospital is at times turned into a hospital ward where desperate patients can wait days to be transferred to a hospital bed..

BELOW: Illegal stem cell experimental treatment is still being provided at Pelonomi Hospital.

Photo: Supplied by anonymous source.

FREE STATE HEALTH

MCC investigation

MCC Chairperson Professor Helen Rees confirmed to *Spotlight* at the time that inspectors had been to the Pelonomi site: "Our concern was that the service level agreement made reference to medicines, injections and therapeutic research."

She said the informed consent documents referred to the patients giving permission for stem cell therapy, permission for stem cells to be removed, concentrated and re-injected and for their stem cells to be given to another person.

The contract at the time stated that the Free State Department of Health and ReGenesis would establish a project management committee consisting of the MEC of Health as Chairperson as well as the CEOs of Pelonomi and Boitumelo hospitals, COOs and representatives from ReGenesis. It reveals that the committee shall meet monthly for the duration of the Agreement to "track progress, resolve pertinent matters to the effective and seamless treatment of patients".

Days after the revelations Free State Premier Ace Magashule reshuffled his Cabinet and Malakoane was shifted from health. Since then, Spotlight have sent questions to the MECs spokespeople and the Premier's people. All these attempts have elicited zero responses.

It is crucial to understand where this case is, has there been an investigation, what are the findings, will anyone be charged, was Malakoane due to benefit from this contract, were proper tender procedures followed, and so on.

A well-placed source in the Free State has shared a list of names of relevant persons who needs to be investigated. They include hospital CEOs who allegedly participated in the scheme, hospital managers who requested the waiting lists and who contacted the patients, doctors and their secretaries who played a key role in running this scheme, a doctor who reportedly gave instructions for the order forms to go through, an individual who gave the financial permissions and two heads at Bophelo House (health department head office) who were involved.

A Bloemfontein doctor said they were aware of patients who suffered due to this treatment, with reports of some dying.

Registrar of Medicines, Dr Joey Gouws recently confirmed that Department of Health inspectors have laid criminal charges against Stander "for the sale of unregistered medicine and or conduct of a clinical trial without obtaining the necessary authorization from the MCC."

Gouws said they were in no position to advise on the status of the police investigation. She also confirmed that the MCC had reported Stander to the Health Professions Council of South Africa (HPCSA). At the time of going to print, the HPCSA had not responded to queries requesting an update on the charges.

Collapse of orthopaedics

More recently *Spotlight* has received information that orthopaedic services in the province are in a state of collapse with a running surgery waiting list at Pelonomi Hospital of over 130 patients (excluding those who have lost faith, packed up and returned home, despite the consequences), on most days.

There are adults with trauma fractures, children with broken limbs and elderly patients with fractured hips. They are lying in overflowing hospital beds and in the passageways on trolleys and on the floor (see photos).

A health worker said that young doctors are facing abuse from frustrated patients who are in limbo, waiting for surgery which does not happen.

This is not the first time the province has faced this problem. In the past the province has been able to reduce the waiting lists significantly by buying in locums at a cost of about R6-million per annum. This is small change compared to what the province was prepared to fork out for the illegal and dangerous Regenesis project.

The domino effect of long waiting lists for orthopaedics is more complications, septic bed sores for the elderly, children left disabled and adults losing their jobs.

A doctor explained that Pelonomi is facing increasing pressure as peripheral hospitals no longer have skilled specialists to do the surgery. The hospital is also taking in referrals from the Northern Cape and Lesotho.

Sources allege that the hospital CEO, Ms Ramadula (a nursing sister) is not disclosing the current state of affairs to the provincial government for fear of reprisals.

"Hospital management are misleading their heads who in turn mislead the national Director-General, who because of incorrect information, misleads the national health minister," a health worker added.

Spotlight contacted the office of the Free State Premier, the Health MEC and the Pelonomi Hospital CEO for comment. Despite several attempts, questons sent to all these office went unanswered. Priscilla Sekhonyana, spokesperson for the HPCSA kept promising to send an update on the charges against Dr Stander, but failed to do so.

Orthopaedic services in the province are in a state of collapse with a running surgery waiting list at Pelonomi Hospital of over 130 patients (excluding those who have lost faith, packed up and returned home, despite the consequences), on most days.

An elderly patient with severe pain waits in the corridor at Kwamhlanga hospital in KwaZulu-Natal without being attended to. The patient's face has been blurred to protect their identity.

KWAZULU-NATAL HEALTH

Hospital horrors

Lotti Rutter & Nora Mathe, Treatment Action Campaign

The hospital is full. Two young girls lie on trolleys in the main hallway. They are wrapped in pink blankets; drips come out of their arms and hang on the walls. One looks in severe agony. She calls out for a nurse again and again. Their mother tells us that they arrived at the hospital seven hours ago and have yet to leave the hallway. Laughter comes from the nurses' break room. It is situated directly opposite their trolleys, but no-one ever emerges to help. →

Photo: Lotti Rutter

A litany of atrocities at Prince Mshiyeni Hospital

+ A wheelchair lies abandoned on the pavement, and trolleys are scattered across the casualty entrance of the hospital. Dirty rags line the floors as we enter. We are greeted by dust, dirt, and dirty chip packets.
+ Family members push patients up and down the hall on trolleys. One patient looks in severe pain, lying on her side on a trolley; she rests her head on a water bottle that acts as a pillow.
+ A diabetes patient waits to collect chronic medicines. Last month she waited through the day until 11pm, only to have to return the next day. Before speaking to us today, she has already waited for over eight hours.
+ Paper files lie on the unattended counter for anyone to look at. One woman waited for eight hours until they located her file.
+ At 4.30pm, more than 100 people still need to be seen. Every corridor of the hospital has more and more patients, sitting, waiting to be attended to.
+ One small room has at least 25 beds haphazardly squashed into it. Another has only a few centimetres between each bed. It seems that psychiatric patients have been put next to other patients.
+ A woman with her leg in a cast had come to the hospital in agony seven hours prior, in an ambulance. The previous month they had cast her leg without having taken an X-ray. At 4.30pm she is told the X-ray department has closed, and she should return the next day. The doctor has not seen her. As she leaves the hospital in a wheelchair, she is still in agony. In her opinion, coming to this hospital is a waste of time.
+ Three people struggle to get an unconscious person – who has been discharged – into the back of a car. They use a piece of material to get the person off the trolley, and eventually, onto the back seat. During this 20-minute challenge, cleaners look on.
+ An old man, looking gaunt and sick, leaves the hospital. A pulled-down TB mask rests on his neck.
+ A hungry man eventually leaves the hospital by getting a lift with strangers. He has been there for eight hours. He has no money for food or for a taxi.
+ A white van emblazoned with a "21st Century Funerals" logo stands outside the accident and emergency entrance. A trolley is carried out of the back and taken inside the hospital. A while later the driver returns, pushing a corpse in a body bag past patients entering the hospital in order to load it into the back of the van.

TOP: Welcome to Prince Mshiyeni Hospital. Expect long waits, bad service and dirty facilities.

CENTRE: Dirty floors in the main hallway.

BELOW: "Wash your hands" – but how without soap and taps?

Photo: Lotti Rutter

An old man with only one leg sits next to them. His drip is attached to the same set of hooks. He stands in pain. He struggles with his crutches, his drip and his file in order to slowly move down the dusty passage to the toilet.

The toilet will not flush, and is dirty after people have tried. A poster haphazardly taped to the wall in the bathroom informs patients that they should "always wash their hands". Yet the soap dispenser is empty, and there are no taps to provide water. The floor is filthy.

Overcrowding, dirty facilities, bad services and poor attitudes. This is what awaits public healthcare users at Prince Mshiyeni Hospital in Umlazi, the largest township close to Durban.

Treatment Action Campaign branches monitor the state of health care at hundreds of clinics and hospitals across the country. They are the people who need the public healthcare system to work, so they are the first to notice when it does not. Prince Mshiyeni Hospital is not alone in its dysfunction. In recent weeks, a TAC fact-finding mission has showcased the crisis in several public hospitals.

We visited hospitals in KwaZulu-Natal, Limpopo, Mpumalanga and Gauteng. And the situation in each is as dire as it is in the next.

In Limpopo, at Malamulele Hospital, people begin queuing at the old and run-down facility from 5.30am. The corridors are full. At each turn, brightly dressed women fill the hallways. Around 200 people are waiting to be attended to by only two doctors. The waiting is unbearably long. We are told that there has been no constant water supply at the hospital for three years. Patients are unable to wash themselves, and there is only a small amount of container water available for using the toilets. As we walk through the wards during visiting hours, the patients have no privacy. There are no doors or curtains. The wards smell, and the bed linen is dirty.

In Tshilidzini Hospital, more than 75 patients wait for their files. Each time a shrill voice screams out a name, the chain of people patiently moves one seat across. People have been waiting in this queue for over five hours. A few people waiting are already wearing Tshilidzini hospital gowns. One is a young man with an open wound on the back of his neck – the wound and stitches are uncovered, and he uses a wad of toilet paper to stop it seeping. And the file room is only the beginning; once they leave, patients are faced with more long queues to be attended to by a doctor.

In Elim Hospital, patients wait for files for around five hours. After collecting their files, they enter the hospital and join a long queue to be seen by a doctor. In a corridor around 100 metres long, patients on back-to-back benches fill the entire space, waiting to be seen. Those with bad coughs sit with everyone else – in a corridor with windows on just one end. As we walk around, at each turn a new queue appears. More faces are raised in hope at the sight of us. In the main hallway, a man is sitting on a trolley, under a blanket. A drip comes out of his arm. He tells us he was admitted six hours ago, but nurses have yet to find a bed for him to be moved to.

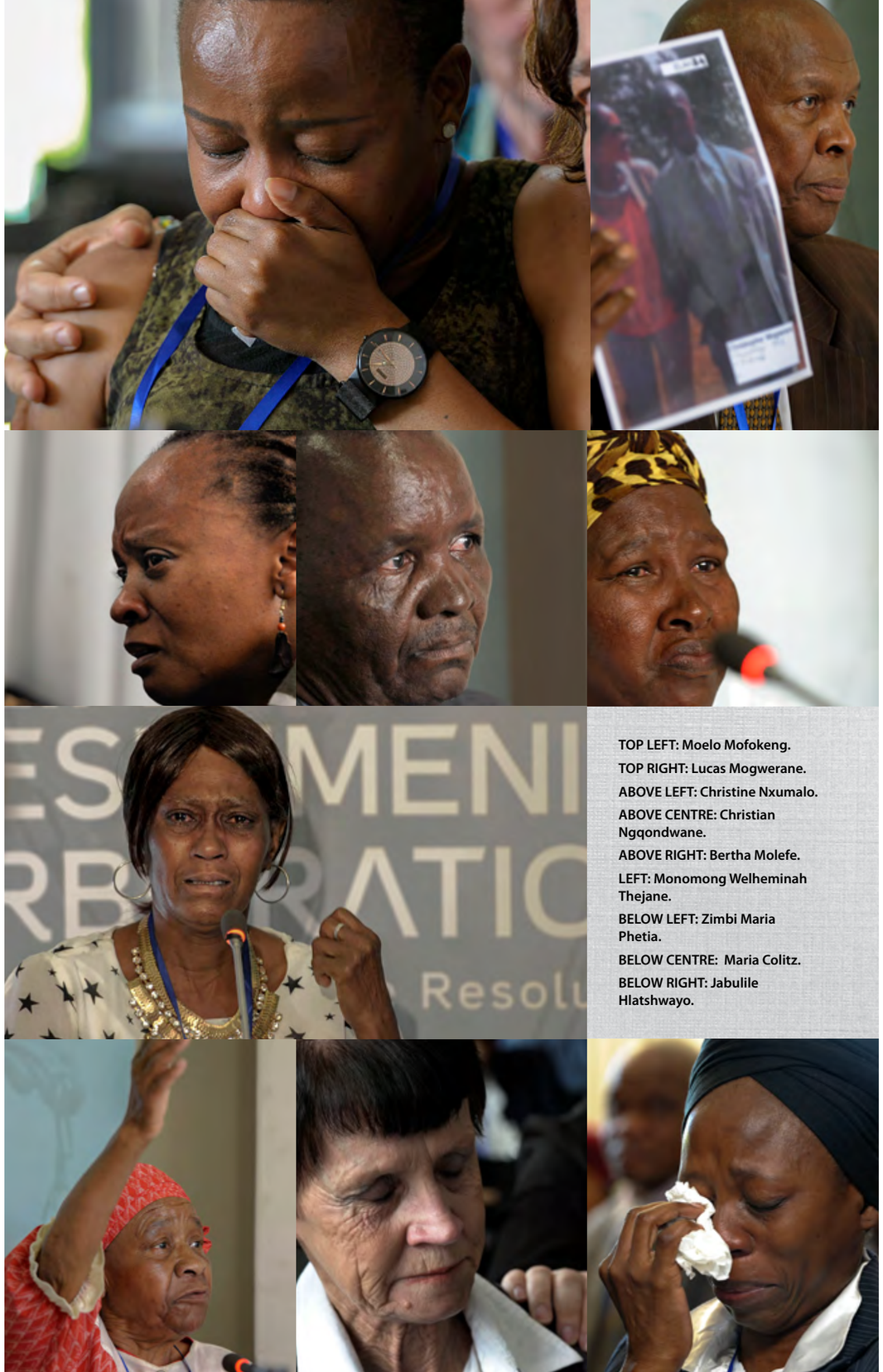
In Mpumalanga, at KwaMhlanga Hospital, the corridors are full. One old gogo (elderly lady) lies on a trolley in the corridor, in severe pain. She struggles to move, and has not yet been attended to. People in wheelchairs are stacked together, each man's knees squashed into the chair in front of him. Hundreds of people wait to be seen. Their eyes follow us as we pass through the corridors. One man sits in casualty with a home-made sling on his arm. After being attacked by thugs, he had attempted to access services at the hospital. An X-ray had been taken the night before – yet only a day later, his file has been lost. He is told to go and submit an affidavit at the police station, and return. He has no money, and has received no painkillers. The young man sitting next to him has been waiting for five hours. A baseball cap covers a bloody stain on the back of his head.

In the most well-resourced province, Gauteng, the recently refurbished Thelle Mogoerane Hospital still suffers the same level of neglect as before. Casualty is overcrowded, and the queues last for hours. People sleep in the corridors. Patients bleeding and in critical condition sit with everyone else. A psychiatric patient is seen wandering around the wards. We are told that for days, patients have been fed porridge for every meal. One woman shows us an X-ray of her broken jaw. She had been sent home with just a Panado for the pain. Another woman told us that post-labour, the doctors had sewn her vagina shut – when she returned to question them, they told her she must have been born that way. Another woman explained how, during labour, doctors took another woman into her space in theatre. Eventually, after waiting the whole day to be seen, she gave birth to her baby. The baby was green, and died six days later.

Poor management, budgetary constraints and a lack of care for the needs of patients plague these public facilities. And it is the people who suffer. In order to expose these crises, and hear from the people who need to use these services, TAC will be holding public hearings and showcasing people's stories in the run-up to World AIDS Day.

As we leave Prince Mshiyeni Hospital through the abandoned trolleys, a woman sits sobbing in a wheelchair. Under a blanket her feet are badly swollen, and she struggles to breathe. We can see the fear in her eyes. She has just been discharged. A nurse leaving the hospital passes by; we try to engage with her to re-admit the woman, but she informs us as she rushes away that she will let the security guard know he must look for the woman's friend. After TAC intervenes, she is re-admitted. Upon being examined, she is diagnosed with pneumonia and cryptococcal meningitis. She is moved to a cold and overcrowded ICU ward, beds mere centimetres apart. She has not been allowed to keep her blanket, and is visibly shaking when we visit.

When we eventually leave the facility, the young girls cocooned in pink are still where we found them in the dirty corridor, hopeless, still waiting for help. .



TOP LEFT: Moelo Mofokeng.
TOP RIGHT: Lucas Mogwerane.
ABOVE LEFT: Christine Nxumalo.
ABOVE CENTRE: Christian Ngqondwane.
ABOVE RIGHT: Bertha Molefe.
LEFT: Monomong Welheminah Thejane.
BELOW LEFT: Zimbi Maria Phetia.
BELOW CENTRE: Maria Colitz.
BELOW RIGHT: Jabulile Hlatshwayo.

Photos: Joyrene Kramer

LIFE ESIDIMENI ARBITRATION

143+ and counting?

Ngqabutho Nceku Mpofu, SECTION27

After two years, and countless attempts at compelling the Gauteng Department of Health (GDoH) to act in the best interests of Mental Health Care Users (MCHUs), significant headway is finally being made in the 'Marathon Project' saga, which saw 1 441 MCHUs rapidly moved from Life Esidimeni – to their detriment. It is an indictment of the GDoH and other powers that be that this is happening a little too late for at least 143 mental health patients, reliant on the public health system, who lost their lives; for their bereaved families; and quite possibly for the 59 patients whose whereabouts are still unknown.

On 9 October 2017, the Life Esidimeni arbitration began. This dispute resolution process, led by former Deputy Chief Justice Dikgang Moseneke, has been geared towards considering adequate compensation, further alternative redress, appropriate psycho-social support, the provision of essential information, and – importantly – closure, where necessary, for families of deceased or affected MCHUs as well as surviving MCHUs.

This process is occurring almost two years after the GDoH announced that it was terminating its long-standing relationship with Life Esidimeni. The need to deinstitutionalise (which is cautiously highlighted in the National Mental Health Policy) and a lack of adequate resources were cited as the primary reasons for the Project. During the arbitration process, both of these reasons have since been debunked.

Life Esidimeni, a private health institution with multiple facilities in Gauteng, had a relationship with the State dating back three decades – to before the dawn of democracy – providing it with services for MCHUs.

The arbitration process has been undertaken as per the recommendations of the Health Ombud, Professor Malegapuru Makgoba, in his report, titled 'The Response into the Circumstances Surrounding the Deaths of Mentally Ill Patients- NO GUNS: 94+ SILENT DEATHS AND STILL COUNTING'. Prof Makgoba found that despite multiple attempts – by experts, civil society, family members and other concerned community members – to dissuade the GDoH from conducting the Marathon Project, the Department proceeded; resulting in the deaths of MCHUs, which may partly be attributed to the abysmal conditions at the Non-Governmental Organisations (NGOs) to which most of the MCHUs were moved. Parties that attempted to ensure that this did not occur include SECTION27, the South African Depression and Anxiety Group (SADAG), the South African Society of Psychiatrists (SASOP), and the Life Esidimeni Family Committee.

The Ombudsman

According to Prof Makgoba, Life Esidimeni was responsible for 1 711 MCHUs. Of those, 270 were discharged to their homes, in line with the policy of deinstitutionalisation; leaving 1 441 MCHUs, most of →

During the arbitration, the Health Ombud revised his initial provisional number of 94 deaths as a result of the Marathon Project, bringing the total to 143 deaths.

whom were transferred to 27 NGOs. During the arbitration, the Health Ombud revised his initial provisional number of 94 deaths as a result of the Marathon Project, bringing the total to 143 deaths (139 of which took place during the arbitration's Terms of Reference). Of these, 29 occurred at Cullinan Care and Rehabilitation Centre (CCRC) facilities (Anchor Ward and Siyabadinga), 38 at Takalani (both complexes), 20 at Precious Angels, and 12 at Tshepong. This translates to a ratio of eight times more than the national average.

Family members and expert witnesses

SECTION27 is representing 66 families whose loved ones passed away as a result of the Marathon Project. The arbitration heard heartbreaking testimony from family members – represented separately by SECTION27, The Legal Aid Clinic and Solidarity – about the state in which they found their loved ones. Rev. Joseph Maboe (80) highlighted the nature of the suffering by relating the story of his son Billy, who was so emaciated when found that he ate the plastic packet from the chips they brought him. Billy passed away days later. Ntombifuthi Dladla related the harrowing story of finding her brother's body in a decomposed state, several months later. In both instances, the families – like many others – had been looking for their loved ones for months, as a result of bureaucratic bungling and lack of rational processes.

Further evidence was provided by Dr Mvuyiso Talatala, a psychiatrist and former President of the South African Society of Psychiatrists (SASOP), an umbrella body representing psychiatrists in South Africa; and Caroline Trotter, a clinical psychologist and psychoanalyst. The former spoke of numerous attempts undertaken to persuade the Department to rethink its approach, while the latter spoke of the inimical effect of the move – mainly on the families of the deceased MCHUs, but to some extent on the surviving MCHUs and their families.

The NGO representatives

The arbitration also heard from Daphney Ndhlovu, a social worker from CCRC; Dikeledi Manaka, a psychiatric nurse from CCRC; Precious Angels owner Ethel Ncube; Anchor Ward owner Dorothy Franks; and former Siyabadinga CEO Dianne Noyile. While their stories varied, marked inexperience, greed, gross neglect and ill-treatment, and lack of the requisite skills were the leitmotifs of their testimony. For instance, Ethel Ncube, whose Precious Angels facility was particularly notorious – 23 out of the 58 patients she received perished – conceded that she only had a certificate in Early Childhood Development, which is an insufficient qualification for looking after adult long-term mentally ill patients. Dorothy Franks admitted during her testimony to receiving R1 500 in monthly SASSA grant payments for each of the 27 patients. These included patients in her NGO who had long since perished there. She also received R600 000, which she accepted, after her NGO was forced to close. Stories abound of patients arriving with limited medicines, no medical records, in buses and cars, occupying overcrowded premises, and having to endure sharing their abode with people of the opposite sex – accentuated by the disparity between able-bodied and non-able-bodied MCHUs, a situation ripe for sexual violence in a country that already has high rates of sexual violence in general.

Gauteng Health Officials

Mr Mosenogi, Project Manager of the Marathon Project and the Director of Planning, Policy and Research at the GDoH, acknowledged his and the Department's shortcomings, apologising profusely and admitting that they had "made mistakes".

At the time of writing, Dr. Manamela – the first of the three senior Department officials identified by the Ombud as having "their fingerprints peppered throughout the project" – was due to testify. The arbitration also looked forward to hearing from other key actors. The former provincial Member of the Executive Council (MEC) for Health, Dr. Qedani Mahlangu; the suspended Head of Department, Dr. Selebano; the Minister of Health, Dr. Aaron Motsoaledi; the Premier of Gauteng province, Mr. David Makhura; and family members representing the surviving MCHUs are expected to testify before the end of the arbitration process on 26 January 2018.

In the final analysis, as powerful an individual story as Life Esidimeni is, it is indicative of a broader malaise affecting the provincial healthcare system. The Gauteng Department of Health has a massive budget deficit, and has not been able to pay major service providers. Nothing short of a full-scale turnaround strategy, in partnership with other stakeholders, is required to ensure the right to health care of public healthcare users in Gauteng.

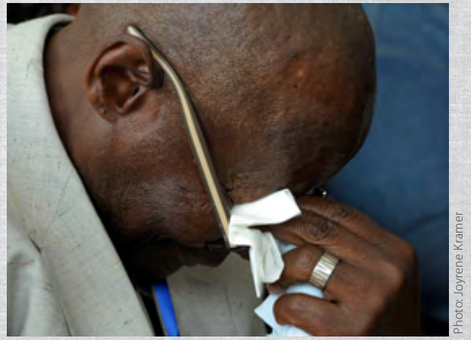


Photo: Joyrene Kramer

TESTIMONY – REV. JOSEPH MABOE (HENDRIK 'BILLY' MABOE)

Rev. Joseph Maboe (80) testified that during the Marathon Project, his oldest child Billy had been transferred from Life Esidimeni to Bophelong, a Non-Governmental Organisation (NGO) in Hammanskraal. This had happened despite the Reverend's explicit resistance through joining the association of concerned Family Residents of Life Esidimeni in 2015, as well as being a part of the legal proceedings against the Gauteng Department of Health.

In his 2015 affidavit, Rev. Maboe stated that Billy had not stabilised at any of four different hospitals until he went to Life Esidimeni, and asked that he not be moved from there. Rev. Maboe was not contacted when Billy was moved, or told to where he had been moved. Billy was only located after he called Rev. Maboe on his (Billy's) birthday.

When the Reverend saw his son, he was "dehydrated; he was hungry; he was filthy; he was smelly"; Rev. Maboe could see "death in his (son's) face". One staff member said that they did not give him water, because they did not want him to wet himself. Billy was so hungry that he ate the plastic packet the chips brought by his father had come in. He was worryingly weak, and could only be taken to the Jubilee hospital two days later, during the week, because a doctor was not on hand to provide a permission note.

Billy died on 22 July 2016, six days after reuniting with his father. The cause of death was indicated to be the result of a lower respiratory tract infection, and therefore 'natural'. This was not sufficient for his father, who felt that the Gauteng Department of Health had been complicit in his son's death.

Photo: Joyrene Kramer

TESTIMONY – NTOMBIFUTHI OLGA DHLADHLA (JOSEPH GUMEDE)

Ntombifuthi Dhladhla (53) testified concerning the circumstances surrounding the untimely demise of her older brother, Joseph Gumede. When she went to visit him in April 2016, Ntombifuthi was shocked to find that Life Esidimeni was closed, as she had not received any communication to this effect. No-one could tell her the whereabouts of her brother.

After traversing different NGOs housing Life Esidimeni patients to no avail, and having engaged with the Gauteng Department of Health (GDoH) for months, she was finally told that they would contact her shortly. According to his death certificate, Joseph had died on 24 July 2016 at Cullinan Care & Rehabilitation Centre (CCRC) in Pretoria. His death was only communicated to his family on 10 February 2017, almost seven months afterwards, when Daphney Ndhlovu, a social worker from CCRC, visited Ntombifuthi to inform them – this despite the fact that CCRC had her details readily available.

Joseph's body had been deposited at a State mortuary in Mamelodi for that time. Unfortunately, according to Ntombifuthi, the State mortuary was not in good working order, resulting in the decomposition of her brother's body.

It was so badly decomposed, Ntombifuthi could hardly identify him. It smelled terribly, and his eyes were not in their sockets. To add insult to injury, the undertaker's car – a minibus taxi – had no trailer in which to put the body. They had to put it across a seat, resulting in flies collecting around it whenever the vehicle stopped at a traffic light. The body was so decomposed, it had maggots spewing out of it, resulting in the undertaker saying that they could not bury him with clothes. His funeral clothes were subsequently placed next to him, and his body wrapped in a blanket.

For Ntombifuthi, her brother did not have dignity in life (post-Life Esidimeni), or in death. She states that moving her brother without essential documents such as his medical records was part of the reason he passed away.

Patients must walk long distances over rough terrain to access even the simplest health services.

SPOTLIGHT ON THE EASTERN CAPE

The Eastern Cape health system has been on the precipice of disaster for several years. Health facilities face the enormous pressure of delivering services to increasing numbers of healthcare users without adequate infrastructure, and with dwindling numbers of healthcare workers. The system is broken, and needs fixing rapidly. The provincial department lurches from crisis to crisis, plugging holes when civil society actors point to deficiencies.

This is not a sustainable solution. We need systematic and structural change. We need better, accountable management. We need more doctors, nurses and support staff; we need a department that cares.

Photo: Ntski Mpulo

Rural communities must eke out a living on social grants and little else, access to healthcare is often unaffordable.

Photos: Rural Health Advocacy Project

EASTERN CAPE HEALTH

Priority-setting, social justice and human rights in the Eastern Cape

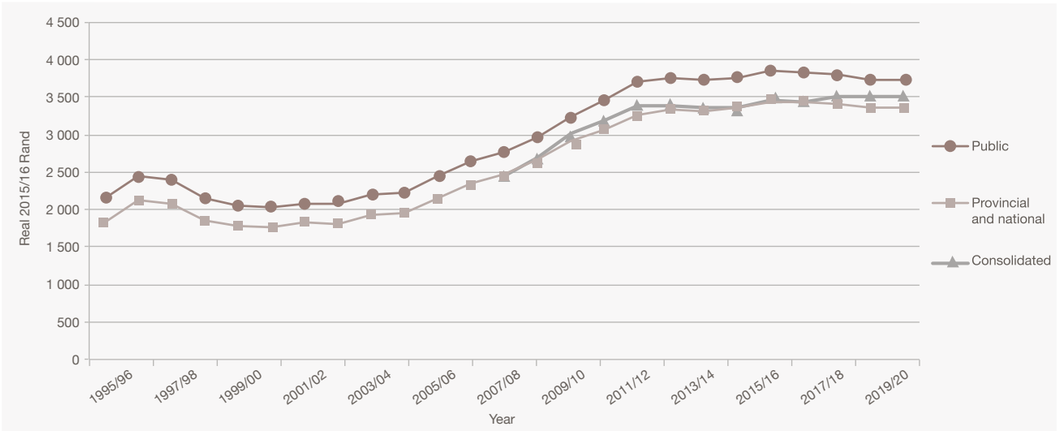
Marije Versteeg-Mojanaga, Rural Health Advocacy Project

The stories of patients and families in this report are devastating. Various factors play a role when patients' rights are violated, including poor planning, inadequate HR management, budget cuts, healthcare worker attitudes, medicine stock-outs, poor policy implementation, and well-intentioned policies that fail to address the rural context.

While there is often an interplay of factors ranging from national down to local issues, ultimately there can be no excuse when lives are lost and people experience great, avoidable suffering. In this article, I make some comments on the relation between systemic factors and deeply entrenched inequities, and on people's struggles in realising their health rights at a local level in the Eastern Cape. I will focus on budgets and Human Resources for Health (HRH)

It is no secret that health overall, including in the Eastern Cape, has been deeply affected by the political and economic crisis that has shaken our country to its core. By Treasury's own admission, as published in the *South African Health Review* (2017), health expenditure has flatlined since 2011/2012:

Real per capita (uninsured) public-health expenditure, South Africa (2015/16 prices)



Source: *South African Health Systems Report 2017*, Heath Systems Trust.

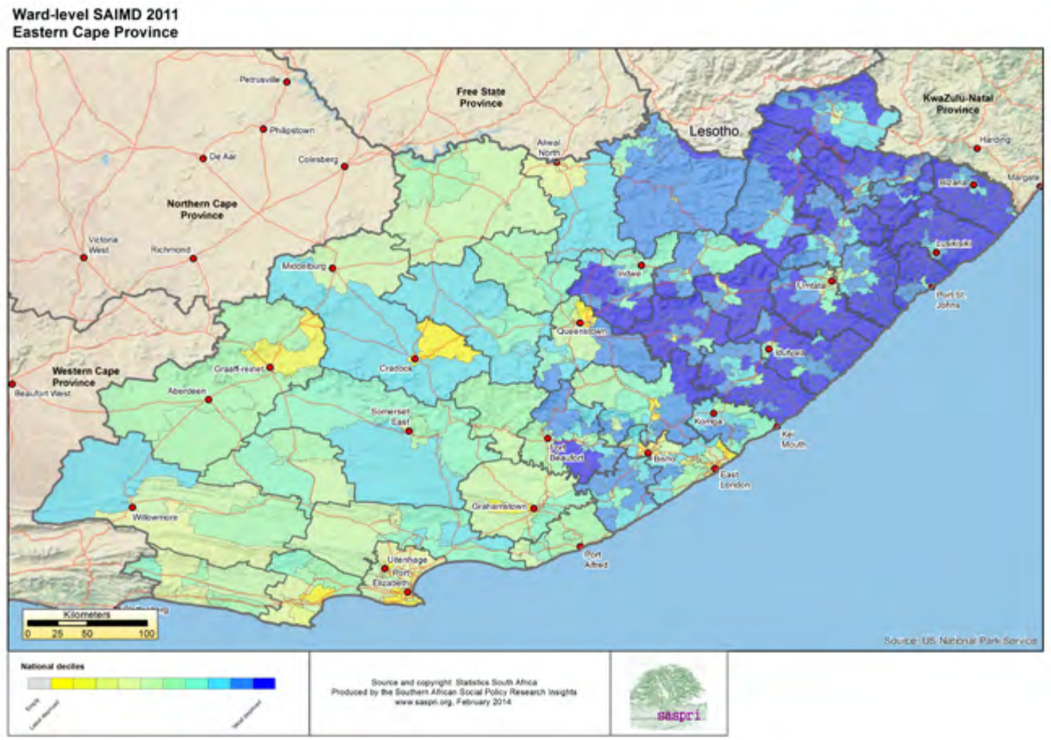
The picture gets worse if we take into account medical inflation, salary increases, new policy priorities and growing medico-legal claim pay-outs in the Eastern Cape – to the tune of R196 million in 2016 – which means that in actual fact, the budget for health has decreased.

In its annual report for 2016, EC Health points to the fact that under-spending in non-core health personnel posts in District Health Services to the amount of R84 255 000 (84 million rand!) has been used to fund the settlement of medico-legal claims – claims that are often caused by health-system failures. While savings on non-core posts complies with Treasury guidelines, having insufficient cleaners, kitchen personnel and procurement officers at the local level does ultimately affect the quality of healthcare services.

No matter how we look at it, →

in real terms the budget for health is decreasing; and this report shows not only how it affects access to health care, but also describes those most deeply affected – namely impoverished communities who often have no alternatives for care, besides digging deeply into personal pockets to book private taxis to facilities further away.

The stories of affected people covered in this report originate from areas in the Eastern Cape that historically have been the most neglected. The map below indicates the persistent inequities affecting this province, with the red lines and dark blue areas representing the former Eastern Cape homelands; people living here today still experience the highest levels of deprivation, from material deprivation (e.g. lack of access to household items, such as a fridge or a phone), to living-environment deprivation (e.g. access to running water and electricity), educational deprivation and employment deprivation (Noble et al, 2014)



Added to these indicators of vulnerability and inequity is the rural context, i.e. terrains difficult to navigate, long gravel roads to facilities, and dispersed populations, which further complicate access to health services for disadvantaged communities.

From a transformative and social justice perspective, government has an obligation to take this background into account when planning healthcare services and prioritising budgets and health personnel. This starts with allocating sufficient funds to health from total revenue. But while the Eastern Cape Department of Health might rightfully argue that its current health budget is insufficient to provide quality healthcare services immediately to all who need them, questions ought to be asked – whether the department, when implementing austerity measures, adequately protects and prioritises those communities most in need, most disadvantaged, and with the least access to resources to protect from further household shocks due to health-service rationing?

In our publication, *Cutting Human Resources for Health – Who Pays* (2017), the Rural Health Advocacy Project reports on its investigation into the impact of budget cuts on spending on human resources for health in OR Tambo District. According to the District Health Barometer (2017), OR Tambo District has the third-highest rate of teen pregnancy in the country, with 11.5% of deliveries in health facilities being to women under the age of eighteen (compared to the national average of 7.4%). This figure reflects poor levels of education and access to reproductive health services, and indicates risk of poor health outcomes for infants and children.

The maternal mortality rate of 198 (per 100 000 live births) is also substantially higher than the national average (133), reflecting poor access to health care during pregnancy, birth and postpartum. This is reinforced by the fact that only 40.7% of mothers delivering in facility record a postnatal healthcare visit within six days of birth.

Tuberculosis is rife in the district, with a reported incidence of 820 per 100 000 population, nearly 30% higher than the national rate of 593 per 100 000. Immunisation coverage in children is also well below government targets in this part of the country, with only 73.2% of all children in a sample of 470 children tracked over time in OR Tambo District being fully vaccinated at 24 months (Le Roux et al, 2017).

We also tell the individual stories of people trying to navigate the health system to seek care for their loved ones; such as a grandmother from Nyandeni Sub-District in OR Tambo, who carries her 15-year old grandchild with cerebral palsy on her back to access the clinic. Soon she will no longer be able to carry his weight. Her grandson is malnourished, and he urgently needs to see a dentist and a dietician and have a change of medication. But the lack of such health cadres locally and the costs of travelling make it impossible for the grandmother to access these types of services. In essence, this means the household is left to fend for themselves.

The hospital rendering care to the people of Nyandeni is Canzibe Hospital, serving a population of 143 000. For a long time, this hospital has not had adequate therapy services for the prevention and management of disability. Within a period of a year the hospital also lost six of its seven doctors – for various reasons, such as completion of community service, and doctors returning to their countries of origin. It took an intensive multi-stakeholder advocacy campaign of 10 months to have the doctor vacancies filled.

In the meantime a lot of harm was done, with sick patients travelling to further-away hospitals at their own cost, or deciding not to seek care at all because of the unreliability of the system and the effort and expense involved. Clinics stopped referring patients, 'as there is no doctor available'. This in turn impacted utilisation rates, which inform budget allocations; and the unmet health need in the community increases.

Canzibe hospital today has no occupational therapists; nor does it have speech or audio-therapists, and 143 000 people rely solely on one part-time volunteer physiotherapist and one assistant. (The creation of therapy Community Service (comserve) posts for 2018 may bring some relief.) However, there is no dentist for Canzibe, and no community health workers, apart from those employed by a very well-run service delivered by an NGO – which covers only two out of 13 wards, but which demonstrate the enormous need for and impact that can made by community health workers.

The situation in Nyandeni Sub-District is just one example of many. While collaborative advocacy made a difference in this case, and helped mobilise resources for health care for this sub-district, health systems planning ought not to depend on outside advocacy. It should be based on rational, evidence-based planning tools that prioritise the most vulnerable residents in the country, first and foremost.

The release of recent organograms in the Eastern Cape makes one hold one's breath for what more lies ahead, with smaller rural facilities facing significant downscaling; leaving a facility such as Canzibe without a CEO position, and more junior staff responsible for time-consuming and important administrative matters, such as motivating for the filling of healthcare-worker vacancies.

An analysis of rehab therapist comserve allocations further reveals very concerning inequities. In 2017, of all community service posts for therapists in the province, 30% were allocated to rural facilities, with posts for 2018 remaining disappointingly low at 31%. What is worse is that some urban facilities receive six or seven therapists, while a facility such as Isilimela Hospital – also in OR Tambo District, and serving impoverished rural communities – has no allocation at all.

To further aggravate the situation, Isilimela did have comserve therapists in 2017. Without any permanent posts and no new comserve posts, where does this leave the current patients of this catchment population? While difficult decisions need to be made when budgets shrink, we cannot take away services.

When we are faced with a financial and political crisis and a shrinking Government purse, how we set priorities matters more than ever. As a collective of citizens, communities, NGOs and other stakeholders, we can question whether health care is getting its fair share; and whether within health we are protecting the most vulnerable. We need to call for innovative solutions, such as free and reliable patient transport services; promote cost-effective measures that will improve access for the people most left out, such as investing in community healthcare workers – which, not unimportantly, also creates jobs that will lift households and communities out of systemic poverty.

But as we have seen, we must be very critical of approaches that focus primarily on utilisation rates and economies of scale, as they discriminate against historically marginalised groups. Beyond maximising health outcomes through cost-efficiencies (utilisation rates and economies of scale), the WHO urges health systems to address two other (equally important) health-system goals: 1) reducing inequities, and 2) minimising the financial burden on patients.

This means taking into account the rural location, whether or not communities can access alternative services without shifting transport costs to patients, and protecting and prioritising poor and marginalised patient groups and communities. Currently, we are performing poorly on these principles of a just health system; and the human impact is staring at us in this report.

We need to call for innovative solutions, such as free and reliable patient transport services; promote cost-effective measures that will improve access for the people most left out, such as investing in community healthcare workers.

Fifteen years without a wheelchair – who pays?

Elin Hem Stenersen, Volunteer Physiotherapist, Canzibe Hospital

A volunteer healthcare worker tells the story of a young boy confined to his bed since he was a young child, as a result of the shortage of physiotherapists and occupational therapists in the rural Eastern Cape. This is a first-person account of the rigours of rural health care, in which it takes extraordinary effort to secure even the most basic services.

Zukile is a 16-year-old boy with severe cerebral palsy who I met in June 2016, through the volunteer work I was doing at a rural district hospital in the Eastern Cape. He hadn`t seen a therapist since he was a year old and was found to have a developmental delay. He had since been lost to follow-up in the system, as rehabilitation services have been almost non-existent at this hospital for many years. Zukile had spent most of his days lying on a bed in his home, his body gradually growing stiff, asymmetric and skewed, with very limited options for interaction with his surroundings.

He is an intellectually present boy trapped in a body that until recently was unable to move very much; but in September 2017, for the first time, Zukile was able to sit up in a wheelchair. Of course, he is not able to sit in the 'perfect' way, because of the years of lying in bed, and not having the proper positioning to stop his body from moving into fixed, asymmetrical positions. His mom now puts him into the wheelchair daily. He especially enjoys sitting outside, watching his brother work in the garden. A basic need such as sitting being met can have a profound impact on the life of a child who has been confined to a bed for so many years.

Zukile's years of suffering could have been prevented, had he been seen sooner by an occupational therapist. Also, I was told that most of the wheelchairs required for children could not be ordered in this financial year, as there was no more money. This means that several children will not receive a wheelchair this year. Will the wheelchair that has been applied for actually fit the child when it finally arrives?

I understand that wheelchairs are costly – especially the specialised ones; but I have witnessed the crucial impact an appropriate wheelchair has on a person`s function and participation in family and community life. An appropriate wheelchair allows one to be in a supported position for eating and social interaction, and to have a chance to get outside and observe one's surroundings. It can also prevent complications, such as contractures, pressure ulcers and aspiration pneumonia – complications that would be costly for the health system and the family, and most importantly, for the person's general health and well-being.

As the sole therapist, on a volunteer basis, for a catchment area of 143 000 people, I am aware that my efforts are a small drop in the ocean. I know my limits, and know that I cannot see and meet all the needs there are; but I can make an impact for one person. I try to see what I can do, rather than what I cannot do. I think that focusing on hope instead of despair and frustration has helped me in many difficult times; because however hard I try, I will sometimes encounter my shortcomings – professionally, administratively, and with regard to time and capacity.

That said, the appreciation and thankfulness I get from the people in the community is heart-warming. Hardly a day goes by without me feeling privileged that I get to be part of something so meaningful and rewarding.

Working in a rural hospital has taught me to value the 'basics' – for example, the importance and impact of basic equipment such as a wheelchair or standing frame, and what it can do in the life of a child or adult with a physical disability. My efforts have been concentrated mostly on the elementary – positioning, with a focus on elements such as pressure care, prevention of contractures, and safe feeding for those unable to feed themselves due to sickness or disability. Applying, fitting, issuing and training users and caregivers in the use of basic equipment and assistive devices such as wheelchairs, standing frames and sidelyers has also been essential. I find appropriate positioning to be critical in creating opportunities for function and participation.

I am thankful for good support from NGOs such as Timion and Malamulele Onward, who have given valuable input and equipment to support children with cerebral palsy. Surrounding hospitals such as Zithulele, Madwaleni and Isilimela have also played an important part, giving me personal and professional support.

Private vehicles delivering patients to Canzibe Hospital.

Photo: Nomatter Ndebele

An issue I would like to raise is my experience with the slow governmental process when it comes to assistive devices, especially wheelchairs. "The right service at the right place at the right time" is often not the practical reality. When I see a patient in need of a wheelchair, that need is now – but the process, from application until the patient receives a wheelchair, can take between one and three years.

In the last quarter of 2015 and throughout 2016, I made about 60 wheelchair applications. Between January and November 2014 there had been no wheelchair applications made, as there were no employed therapists to make them. I am not sure how and when people in need of wheelchairs would receive this service, without having therapists in the area.

In September 2017 I received the first special wheelchairs for adults – two of these had been applied for in December 2015. Before then, the only available adult wheelchairs had been the basic folding-frame wheelchairs, which are highly inappropriate in an area in which the environment features gravel roads, paths and fields, with households on steep hills and in deep valleys, at times kilometres away from a basic gravel road. In Detyana community, I visited two young men with paraplegia who are unable to get out into the community without assistance. Getting to town, the hospital or the clinic is a costly affair, as the few local taxis will not pick them up; they must book special transport, at a cost of about R200 one way.

I have attended basic and intermediate wheelchair courses at the Western Cape Rehabilitation Centre, where there is talk of 'the appropriate wheelchair', and the human rights of people with disabilities, and that a wheelchair needs to be the right fit with the appropriate function. For me, this has created a dilemma: should I think of cost, and continue to apply for inappropriate, basic folding-frame wheelchairs for the many? Or apply for wheelchairs that have been designed for rural areas? Yes, they cost more – but they allow increased mobility for the user, and they last longer. A basic folding-frame wheelchair can last an active wheelchair-user between six months and a year. A rural, rugged-terrain wheelchair, if looked after well, can last a user between two and three years. Power wheelchairs are even less accessible, as they are quite expensive; but if this is the appropriate wheelchair for someone in a rural area, why should they not have access to it?

I was confronted with this dilemma when I forwarded my special-wheelchair applications to the regional administrator. Do you settle for the basic model, so that more people can get a wheelchair in a shorter time? Or do you apply for the appropriate choice, knowing that fewer people will receive wheelchairs?

I cannot compromise! I will apply for the most appropriate model; because the purpose of a wheelchair is to provide support, facilitate function, and give hope to people like Zukile – who is now no longer confined to a bed, but sits proudly in the sun, part of his family's daily life.

TOP: The collapsing shell of what used to be Hamburg Clinic. Slow and erratic constuction work on the new building continues as Keiskamma Trust temporarily houses the clinic.

LEFT: A bakkie is used as A make-shift ambulance at Butterworth Hospital.

ABOVE: A hopeful Philani Clinic nurse placed a sign where the ambulance must park – if and when it ever arrives.

BELOW: The Village Clinic, under construction since 2013 – delays have been caused by contractor issues.

Photos: Ntsiki Mpulo & Anso Thom

EASTERN CAPE HEALTH

Two steps forward, three steps back

Ntsiki Mpulo, SECTION27

Eastern Cape Health Department fails to complete clinic projects promised by the Minister of Health.

Hamburg Clinic

The shell of the former Hamburg Clinic stands atop a hill overlooking the Keiskamma River. The 30-year-old structure fell down in 2012, as a result of strong winds. In 2017, after five long years, the Eastern Cape Health Department – in partnership with the Coega Development Corporation (CDC) – began the construction of a new clinic. According to the department's spokesperson, the project is due to be completed in a year's time.

On the day we visited, the site was abandoned. Our source tells us that construction – which began in July 2017 – has been slow and erratic. When it rains, workers do not come to work. This does not bode well. It is unlikely that the clinic will be completed in the timeframes promised by the department. In the meantime, Hamburg Clinic is housed in the Keiskamma Trust building.

Pilani Clinic in Canzibe

The gleaming white floors and the shiny new chairs mask the reality faced by the healthcare users of Pilani Clinic, near Ntshilini village. The clinic was overhauled and rebuilt following the publishing of the *Death and Dying* report in 2013, when Health Minister Aaron Motsoaledi was alerted to among others the dire circumstances under which nurses operated in the clinic.

Asbestos heaters have been removed. New sluice facilities have been built. The clinic has a pharmacy storage unit, replete with chronic medication. But all is not well.

The nurses are forced to use old equipment, which was not replaced during the refurbishment. The newly built staff quarters have no furniture. The clinic, which serves communities from Ntshilini all the way to Canzibe, is staffed by two professional nurses and a couple of community health workers, who are not employed by the department. There is no doctor rostered to visit the clinic.

In a recent case in which a two-year-old was burnt by hot water, the sister on duty did what she could to clean the wound, but had to refer the child to Canzibe Hospital, some 40 kilometres away. This is a daunting journey on any day, because the roads are so poor; and as there is no ambulance in the area, the child's parents were forced to hire a car, at exorbitant cost.

The enterprising Sister Sylvia, who has worked at the clinic for over 11 years, has placed a sign where the ambulance ought to park – if and when it ever arrives.

Village Clinic

Two years after Eastern Cape Health Crisis Action Coalition (ECHCAC) visited the construction proposed for the Village Clinic in Lusikisiki in the Eastern Cape, the clinic is still not open.

This clinic has a long and complicated history. Since 2005, it had been housed in a building formerly occupied by AngloGold Ashanti; which was ideal, as it was located in the centre of town, and had private consultation rooms, a waiting area, bathrooms and a pharmacy.

Bizarrely, in December 2012 the Eastern Cape Health Department (ECDoH) closed the clinic down, and relocated it to a site just outside of town. From then on, two porous tents and a mobile home would serve as the clinic for the people of Lusikisiki.

The Treatment Action Campaign (TAC) and ECHCAC embarked on a series of protests, and enlisted the help of SECTION27 to begin a process of litigation. The TAC filed a lawsuit against the ECDoH on 29 May 2013, in which it named the Minister of Health as respondent. The Minister, on seeing pictures of the tents that comprised the clinic, tabled a plan to put up a temporary structure by July 2013, and to build a large, permanent clinic in the following eight to 12 months.

Since the temporary structure was erected in 2013, the people of Lusikisiki have been without a building for their clinic. They wait in the rain and the cold for their medicines, which are housed in a trailer with no refrigeration; and there are no private consultation rooms. Contractor issues have resulted in endless delays in the construction of the new clinic.

In August 2017, the contractor declared itself ready to hand the clinic over; however, the Department of Health deemed it incomplete according to its standards. At the time of writing, it was unclear when the clinic would finally be ready to open.

Keiskamma Trust which survives on donor funding is facing a crisis as money dries up for it Community Health Worker programme

Photo: Keiskamma Trust Facebook page.

EASTERN CAPE HEALTH

Lifesaving programme under threat

Ntsiki Mpulo, SECTION27

Keiskamma Trust, an Eastern Cape based health organisation, praised around the world for its incredible community work which has saved thousands of lives, is in danger after funding cuts. *Spotlight* spent time with a community worker to give us a glimpse into the important work they do in a province where the health system is unable to deliver.

"The magnitude of the HIV/Aids challenge facing the country calls for a concerted, co-ordinated and co-operative national effort in which government in each of its three spheres and the panoply of resources and skills of civil society are marshalled, inspired and led."

This was the rallying call of the judgment in Minister of Health vs Treatment Action Campaign, in 2002. Following years of AIDS denialism, the court upheld the constitutional right of all HIV-positive pregnant women to access healthcare services to prevent mother-to-child transmission of HIV (PMTCT).

Dr Carol Hofmeyer, a medical doctor who had settled in the Eastern Cape town of Hamburg, heeded the call, and began administering lifesaving ART (anti-retroviral therapy) to the people surrounding the village. The programme started with a handful of community health workers supporting the AIDS hospice. They now have 80 community health workers who serve 47 villages and 13 clinics in the Amathole District area surrounding Hamburg, including Peddie and Nier Village.

Nontobeko Twane, a community health worker based in Mgababa village, started as a volunteer at Keiskamma Trust in 2006. She received training as a community health worker, and was then employed on a permanent basis. She hasn't worked elsewhere, and the stipend she receives is her only source of income.

She tested positive for HIV in February 2008, and was initiated on treatment in May 2008. She has steadfastly taken treatment since that day, and continues to do so today. She understands the challenges related to taking chronic medication for the rest of her life, and is thus able to provide the support that her patients need.

She is based largely at Keiskamma Trust, which is the temporary home of Hamburg Clinic. The Trust stepped in and offered its premises as a temporary measure when the 30-year-old Hamburg Clinic building collapsed in 2012. Through this collaboration, the Keiskamma Trust community health workers have developed a close working relationship with the clinic sisters.

The services provided by the Keiskamma community health workers include home-based care visits, regular reporting to nursing staff on critical cases, and monitoring adherence to (but not limited to) ARVs and TB, hypertension and diabetes medication. Now, these services are in jeopardy, as the Keiskamma Trust faces a funding crisis.

Following the termination of a donor-funding agreement, the trust is no longer able to pay the community health workers who are part of the programme, which requires R1.2 million per annum in operational funding. The Eastern Cape Health Department has agreed to provide sufficient funding to pay 10 community health workers per annum. This falls far short of the funds required to pay stipends for the 80 community health workers in the programme.

The Keiskamma community health workers are the cornerstone of the success of the health programme in the area; without them, women such as 27-year-old Zukiswa (name changed) face certain death.

Zukiswa lives in Mgabaga Village with her husband of five years, Moses (name changed), and her two children – a three-year-old daughter and a one-year-old, son Her husband works as a mechanic, fixing cars in the yard of their small home. Zukiswa does not work, and the family's only other source of income is the child grant received from the state. However, this is insufficient to feed the entire family; it covers formula and nappies for the youngest child, and a modest amount of food. Zukiswa's emaciated frame is testament to this fact.

She says that she has always been slight in build; but what is clear is that Zukiswa is wasting away. She tested positive for HIV in 2015. She was initiated on treatment, but has since stopped taking her medication. Her reason for not taking her medication is that there is no food in the house.

Zukiswa cowers on the corner of the couch, the only piece of furniture in the lounge, while Nontobeko perches on a bench opposite her. Though it is not stated openly, it is clear that Zukiswa is afraid of her husband. Moses has also tested positive, but has opted not to start ARV treatment. This increases the chances that Zukiswa a will become re-infected if she does not resume her treatment.

On numerous occasions, Nontobeko has explained to Zukiswa that taking her medication means that she will increase her life expectancy, so can she raise her children. She has on occasion requested support from the Department of Social Development, to provide food parcels; however, this has only been a stopgap measure. And as Zukiswa continues not to adhere to her treatment, Nontobeko is fearful that this young mother will not survive the year.

Nontobeko, like the other 80 community health workers employed by Keiskamma Trust, provides a lifeline for the women she looks after. Without her, many would be unable to access health care at all. .

EASTERN CAPE HEALTH

Philani Clinic – A timeline of failure

Ntiski Mpulo, SECTION27

A few meters from the entrance to Philani Clinic in Queenstown, opposite the gate, is a black-walled tavern. On weekdays, it's as quiet as a church; but on weekends, music bursts out of its dark interior, cars line the street and patrons dance between them, holding beer cans and bottles.

The gates of the clinic are not secured, so anyone from the tavern is free to wander in; there is but one security guard on the premises. This poses a significant risk to the patients and nursing staff of the clinic.

"When we work on weekends, the drunks come and harass us," says Sister Annelise Koti. "I don't feel safe at all."

Traditionally, the clinic opened from 08:00 till 16:30 on weekdays. Since 2013, following a directive from then-MEC for Health Sicelo Gqobana, nurses at Philani Clinic were instructed by the sub-district manager, Nonceba Bhabha to begin working weekends and public holidays.

The nurses have been forced to work on weekends without compensation, and this is taking a toll. Four nurses have resigned or been fired since this unilateral decision was handed down from the district office, leaving only eight nurses rotating shifts to cover weekends. On any given day, there should be three nurses at the clinic; because of staff shortages, only two nurses work on weekends.

The nurses have questioned the decision to operate seven days a week, and have requested written confirmation from the district manager that this was indeed mandated by the department. A memorandum from the district manager to the superintendent-general confirms that the resolution to open the clinic on weekends was never signed.

"We requested the minutes of this meeting," explains Sister Koti. "We also asked for a policy that we should work extended hours, and we asked hat we would be paid for public holidays and weekends."

The sub-district manager did not respond to their requests. Instead, according to Sister Koti, pressure was placed on the operational manager.

"She said we must comply, and complain later. She never gave us options for contesting this thing," says Koti.

"We asked them to give us something in writing to cover us if anything happens," she says. "For example, there could be a medico-legal claim against one of us, and we wanted to be covered. The department of health will deny you. They will say, 'You asked to work weekends yourselves.'"

Nurses' pleas fall on deaf ears

Nurses at Philani Clinic report being subjected to victimisation from the district office. They have repeatedly asked their union representatives to intervene on their behalf, with little progress in resolving the issue.

"In 2015, when we spoke with the unions, suddenly the minutes emerged," explains Koti. "But these did not specifically refer to Philani Clinic operating for seven days a week. They said in the minutes that they were preparing for opening 24 hours. But we said, 'You can't prepare for 24 hours with such old infrastructure. This is an old clinic.'" →

The gates of the clinic are not secured, so anyone from the tavern is free to wander in; there is but one security guard on the premises. This poses a significant risk to the patients and nursing staff of the clinic.

CLOCKWISE FROM TOP LEFT: Peeling paint welcomes patients; flithy floors and missing fire extinguishers; empty chairs on the weekend while nuirses are forced to be on duty without pay; storage room in disarray; rising damp throughout the old building; and a rubbish dump right outside the clinic.

Photos: Ntiski Mpulo & Vuyokazi Gonyela

The clinic is over 100 years old, and badly maintained. Paint peels off the wall where damp is creeping up from beneath the ground. The foundation is reportedly sinking. A memorandum from the clinic committee states that there is often no water available; the clinic is equipped with a rainwater tank, which runs empty and is not refilled. The memorandum also cites insufficient equipment, including a fax machine that has been without ink for nearly five years.

The clinic has been the site of contention in the last three years, with residents forcing it to be closed on several occasions. The reasons for the shutdown are numerous; clinic committee member Luyanda Nogemane places the blame squarely on the unresponsive stance taken by the MEC for Health, Phumla Dyantyi. He claims that Dyantyi has placed politically connected individuals at the district office, instead of people who care about the community.

On 30 November 2016 the committee wrote a letter to Dyantyi, accompanied by 68 signatures. However, the matter remains unresolved.

The community shut the clinic for a day in March 2017, then again in May and June of that year, citing the non-payment of nurses as one of the key issues. "We took our grievances to Bisho, and met with Mr Myezo," says Koti.

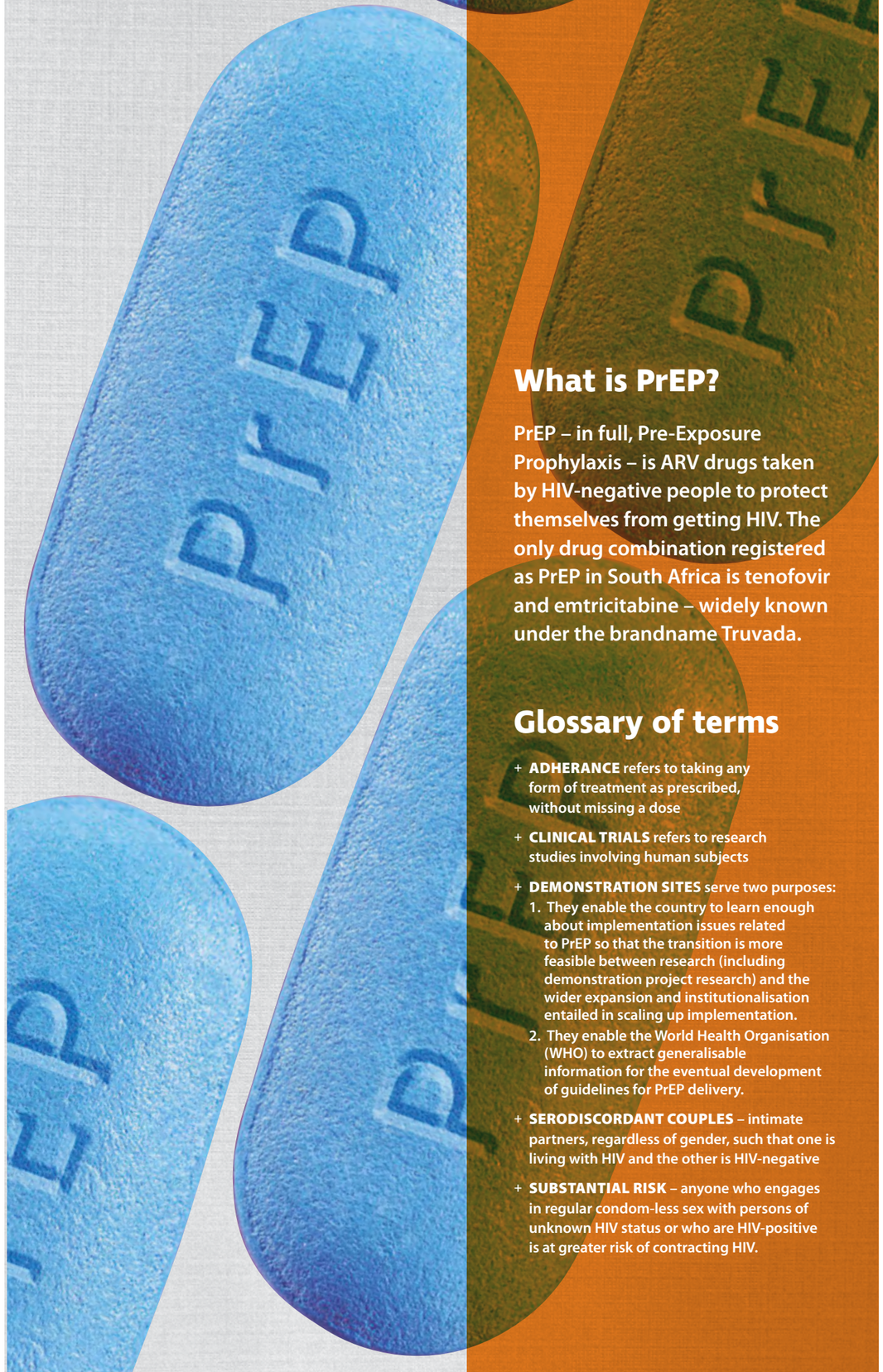
The HR manager called a senior manager at the district office and was told that the nurses had been paid. He advised them to set up a memorandum of understanding between the nurses and the district, but this has not been put in place. Instead, the district office issued notices stating that the nurses were off duty without authorisation, and began withdrawing money from their salaries – amounting to as much as R1 500 – if they did not report for duty on weekends. At that time, Eastern Cape Health Department spokesperson Sizwe Kupelo is reported to have said that payments to the nurses were not completed because the nurses had not submitted claim forms – but Sister Koti tells a different story.

"They targeted us," says Koti. "In April they withdrew the money. The HR clerk would bring 'leave without pay' forms, which we refused to sign."

Staff morale at the clinic is at an all-time low. Those who remain are burnt out. Between the three nurses on duty, they serve approximately 200 people per day; and on the weekends, when there are only two nurses on duty, there is no clerk to receive patients, so this task must also be performed by the nurses.

"We try not to let our issues affect the clients," explains Koti. "Although clinic hours are 08:00 to 16:30, it is rare for us to leave at that time. We stay till after 6pm sometimes. We often don't have time for lunch – forget about tea breaks.

"We want to be treated with dignity," says Koti. "We have families too."



What is PrEP?

PrEP – in full, Pre-Exposure Prophylaxis – is ARV drugs taken by HIV-negative people to protect themselves from getting HIV. The only drug combination registered as PrEP in South Africa is tenofovir and emtricitabine – widely known under the brandname Truvada.

Glossary of terms

+ **ADHERANCE** refers to taking any form of treatment as prescribed, without missing a dose
+ **CLINICAL TRIALS** refers to research studies involving human subjects
+ **DEMONSTRATION SITES** serve two purposes:
  1. They enable the country to learn enough about implementation issues related to PrEP so that the transition is more feasible between research (including demonstration project research) and the wider expansion and institutionalisation entailed in scaling up implementation.
  2. They enable the World Health Organisation (WHO) to extract generalisable information for the eventual development of guidelines for PrEP delivery.
+ **SERODISCORDANT COUPLES** – intimate partners, regardless of gender, such that one is living with HIV and the other is HIV-negative
+ **SUBSTANTIAL RISK** – anyone who engages in regular condom-less sex with persons of unknown HIV status or who are HIV-positive is at greater risk of contracting HIV.

The state of PrEP access in SA

Thuthukile Mbatha*, SECTION27

Young women between the ages of 15 and 24 years are among the key population groups with the highest risk of contracting HIV. It is estimated that about 2 000 HIV infections occur weekly in South Africa among this group.

A number of HIV-prevention campaigns have been targeting the youth out of school. Young women between the ages of 15 and 24 years in higher education institutions are usually the last ones to find out about such initiatives. The assumption that young women in higher education institutions are more knowledgeable about HIV prevention – and therefore more responsible – is false. They are as vulnerable as the young women out of school.

South Africa has a number of HIV-prevention interventions that were introduced to try and curb the increasing number of HIV infections in the country. These include female and male condoms, medical male circumcision, treatment as prevention, Post-Exposure Prophylaxis (PEP), and recently, Pre-Exposure Prophylaxis (PrEP).

PrEP is not yet widely accessible in the public sector South Africa. It can only be accessed through demonstration sites, clinical research institutes, and the private sector. A month's supply of a daily dose of PrEP costs between R300 and R550 from the private sector. However, not all medical aids will cover the costs.

PrEP is only given to HIV-negative people who self-identify as being at substantial risk of acquiring HIV. The demonstration sites have seen a very low uptake of PrEP by the key population groups. This has raised concerns about providing it to young women, as they too may have a hard time adhering to the dosage regime; in other words, they may not take it as prescribed.

Any introduction of a new prevention product or intervention meets a lot of scepticism from the targeted population to begin with. Many clinical trials have been done that have shown that a lot of interventions work; however, they all experience a low uptake at first. The female condom, for instance, has been around for several years, but has been under-used. There have been many campaigns and initiatives highlighting the importance of medical male circumcision, shown to decrease the chances of contracting HIV among men by 60 per cent; however, we are still seeing only a relatively slow increase in the number of young men being circumcised.

What have we learnt from past experiences? Are we still employing the same strategies that we applied in previous interventions? The US is one of the first countries to roll out PrEP; they also saw a low uptake at first, but it has been improving gradually.

The scepticism seen is fuelled by the failure of PrEP in some clinical trials, such as those for FEM PrEP and VOICE – both of which involved women. These studies were testing the effectiveness of oral PrEP among women at higher risk of contracting HIV. They had to be stopped early when it became clear that the studies would not be able to show whether or not the pill prevented HIV acquisition (due to low treatment adherence in the trials).

However, the main reason for this was found to be low adherence. The women in these two studies were not taking the PrEP as prescribed. This conclusion was supported by evidence of very low drug levels in their systems; another reason is that they did not perceive themselves as being at greater risk of contracting HIV. According to the World Health Organisation (WHO), a person must take the PrEP pill daily for at least seven consecutive days before they are fully protected, and then continue taking it daily.

However, subsequent trials showed that in fact, PrEP does reduce risk in women. The Partners demonstration project was done using serodiscordant heterosexual couples as subjects, and proved effective. These are couples in which one partner is HIV-positive and on treatment, and the other is HIV-negative. →

PrEP is not yet widely accessible in the public sector South Africa. It can only be accessed through demonstration sites, clinical research institutes, and the private sector. A month's supply of a daily dose of PrEP costs between R300 and R550 from the private sector.

PrEP

Some people are concerned that providing PrEP to young women will lead to promiscuity. However, there is no evidence of this among those taking PrEP. Furthermore, PrEP itself reduces the risk of HIV very effectively, so sex on PrEP should not be seen as 'unprotected'. Sex on PrEP is 'barrier-free', perhaps, but certainly not unprotected or unsafe.

There's a need here for a paradigm shift when discussing what is and isn't 'safer' sex. Unlike condoms, which protect the user from pregnancy, STIs and HIV infection, PrEP only protects against contracting HIV. Someone taking PrEP would still need to use a condom or some other form of contraception as part of a combination prevention method.

As women, we value choice. For example, the decision to use Depo-Provera over an Intra-Uterine Device (IUD) as a family planning method lies solely with the individual. Young women in higher education institutions are no exception. They too need to be afforded the opportunity to choose which HIV-prevention option is best for them.

Studies have confirmed that PrEP works if you take it. So why are we not rolling it out to all young women at substantial risk of acquiring HIV? The alarming pregnancy rates in higher education institutions indicates low use of condoms and other family planning methods.

Providing PrEP to only a select group of people is not getting us anywhere. The country continues to see rising HIV infections among young women aged between 15 and 24 years. How many more infections do we have to see before we scale it up? Let's equip young women with access to the best HIV prevention, and with the knowledge that will enable them to make informed decisions. The inclusion of PrEP into a comprehensive sexual and reproductive health package is the first step. PrEP campaigns should go hand in hand with campaigns to promote HIV testing and other available HIV-prevention tools.

*Thuthukile Mbatha is a researcher at SECTION27, and an advocacy fellow for the AIDS Vaccine Advocacy Coalition (AVAC). She runs an advocacy project that calls for access to Pre-Exposure Prophylaxis (PrEP) for young women in higher education institutions.

AGE, GENDER AND CYCLES OF TRANSMISSION

Professor Quarraisha Abdool Karim**, CAPRISA

One in five people with HIV – or who have newly acquired HIV – lives in South Africa, despite it being home to less than 1% of the global population.

The use of phylogenetics to understand the infection of HIV highlights that about 24% of young women under 25 years of age do not know their HIV status; and about 60% are acquiring HIV from male partners who are on average eight or more years older than them, i.e. in the 25 to 40 age group. The majority of men of 25 to 40 years old are unaware of their HIV status and have high viral loads, suggesting recently acquired infection and hence higher transmission rates.

Young men are acquiring HIV from already infected women 25 to 35 years of age; on average, the age difference in these cases is about a year. About 40% of men 25 to 40 years old are having sex with women younger than 25 and women older than 25 concurrently, thus perpetuating these cycles of transmission. Preventing HIV infection in young women under 25 years will require a multi-pronged approach that includes Sexual and Reproductive Health Rights services to young women; finding the missing men (who do not access health services); and treatment of women older than 25.

Preventing HIV infection in adolescent girls and young women could change the course of the epidemic in Africa, and reverse the current poor global progress in HIV prevention. Oral tenofovir, alone or in combination with emtricitabine (PrEP), is the only woman-initiated prevention technology that does not require partner knowledge or co-operation. We cannot afford not to make this prevention option available to young women.

** Professor Quarraisha Abdool Karim, Associate Scientific Director of CAPRISA in South Africa and one of the world's foremost scientists on PrEP.

PrEP

PrEP in higher-education institutions

Thuthukile Mbatha, SECTION27

1 October is set to become a memorable day in some higher-education institutions. It marks the day in 2017 that Pre-Exposure Prophylaxis (PrEP) was first rolled out at select campus health clinics as a new, highly effective HIV-prevention method.

PrEP is an ARV drug combination taken to prevent infection by HIV-negative people who are at a greater risk of acquiring HIV. The two drugs in the only registered PrEP pill in South Africa are tenofovir and emptricitabine – also known under the brandname Truvada.

The provision of PrEP in South Africa occurs through various sites, these include the national health system, demonstration projects, large scale implementation initiatives (i.e. Dreams project) and the private sector. The Department of Health (NDoH) has identified seven higher education institutions that will form part of the above sites in rolling out PrEP to young people.

These institutions are the University of Free State, the University of Venda, Rhodes University, Nelson Mandela University, the University of Zululand, the University of Limpopo and Vaal University. Not all of them began rolling out PrEP on the set date; however, all these institutions were selected because they met the criteria set by the National Department of Health to assess their state of readiness to provide primary healthcare services to students.

A number of factors must be considered when determining whether an institution is fit for PrEP roll-out. These include staffing, qualification of nurses, dispensing licences and adequate storage, to name a few. The seven institutions currently providing PrEP are already dispensing antiretroviral treatment (ART) to students living with HIV, as well as other primary healthcare services, which was another prerequisite for PrEP provision. Many institutions do not offer this service for the reasons listed above, among others.

It is important for professional nurses to have a primary healthcare qualification, and also to acquire a dispensing licence. This enables them to deliver primary healthcare services, including ART and PrEP initiation. The provision of such services is usually supported by the District Department of Health office. Only the institutions that pass the assessment are considered as PrEP roll-out sites. In the institutions listed above, extensive training of clinic health personnel and peer educators was done to ensure readiness for PrEP provision and demand creation in these institutions. However, students have not yet been properly engaged, as the roll-out was introduced at what was a very busy time for students, who were preparing for exams. These institutions aim to intensify their demand-creation campaigns in the new year.

Most institutions fund the operation of their own campus health clinics; however, the Department of Health supplies them with family-planning and STI medicines. "We had to sign a memorandum of understanding with the Department of Health in order for them to supply us with PrEP," said a health professional at one of the institutions.

"We do not have a set target number of students to provide PrEP to – every student who comes to our clinic and requests it is given it, after doing an HIV test and establishing that the student is HIV-negative," she added.

The seven higher-education institutions that have started rolling out PrEP are an addition to the 17 demonstration sites providing PrEP that were established from June 2016. These demonstration sites include clinics for sex workers and for men who have sex with men (MSM). South Africa's approach to PrEP roll out is focusing on targeting these 'key population' groups. For groups of people considered to be key populations, see www.avert.org/professionals/hiv-social-issues/key-affected-populations

Truvada (or any other tenofovir-based regimen) as PrEP is still not included in the South African Essential Drugs List (EDL). Its inclusion in the EDL would bring down the costs of PrEP, which would make it cheaper for the National Department of Health to provide sustainably to people who need it.

It is also important to note that the state of readiness for PrEP varies from institution to institution. Institutions such as the Technical and Vocational Education Training (TVET) colleges do not have campus health clinics, therefore they rely on off-campus clinics for sexual and reproductive healthcare services. The future roll-out plans should also consider such cases. A proper audit of all campus and off-campus clinics is required, so that all the issues may be addressed before the scale-up of PrEP roll-out.

Moreover, for PrEP roll-out to be effective, the inclusion of Student Representative Councils is very important, because of the power of influence they possess. It is critical to have student involvement in the entire process, to ensure a more positive uptake.

PrEP

Why I take PrEP

Nomnotho Ntsele*, student

When I first heard about PrEP, I thought it was meant for promiscuous people – I did not think it was for me at all. The fact that it was only available to sex workers supported my assumptions. I did not understand that anyone could be at substantial risk of contracting HIV, especially young women my age. My opinion changed when I attended the Youth Dialogue in Prevention at SECTION27 in September, where I learnt a lot more about the science of PrEP, and realized that even I am at risk of contracting HIV.

I then started reading more about it, and incorporated the information I learnt in my peer-education work. I started telling other students in my institution about this other option for HIV prevention. Following my residence visits and talks, I was approached by students in serodiscordant relationships (where one partner is HIV-positive and the other HIV-negative) asking about where to access PrEP. I remembered that at the Youth Dialogue, we were told that the Centre for the AIDS Programme of Research in South Africa (CAPRISA) and the Wits Reproductive Health & HIV Institute are currently offering it to young women who are not part of clinical trials. I therefore referred them to CAPRISA.

As I myself am in a long-distance relationship, I realised that I am also at risk of contracting HIV. Moreover, I was curious to know how this PrEP pill works. I wanted to be able to address students' concerns about side effects and other related questions. And maybe PrEP was for me too?

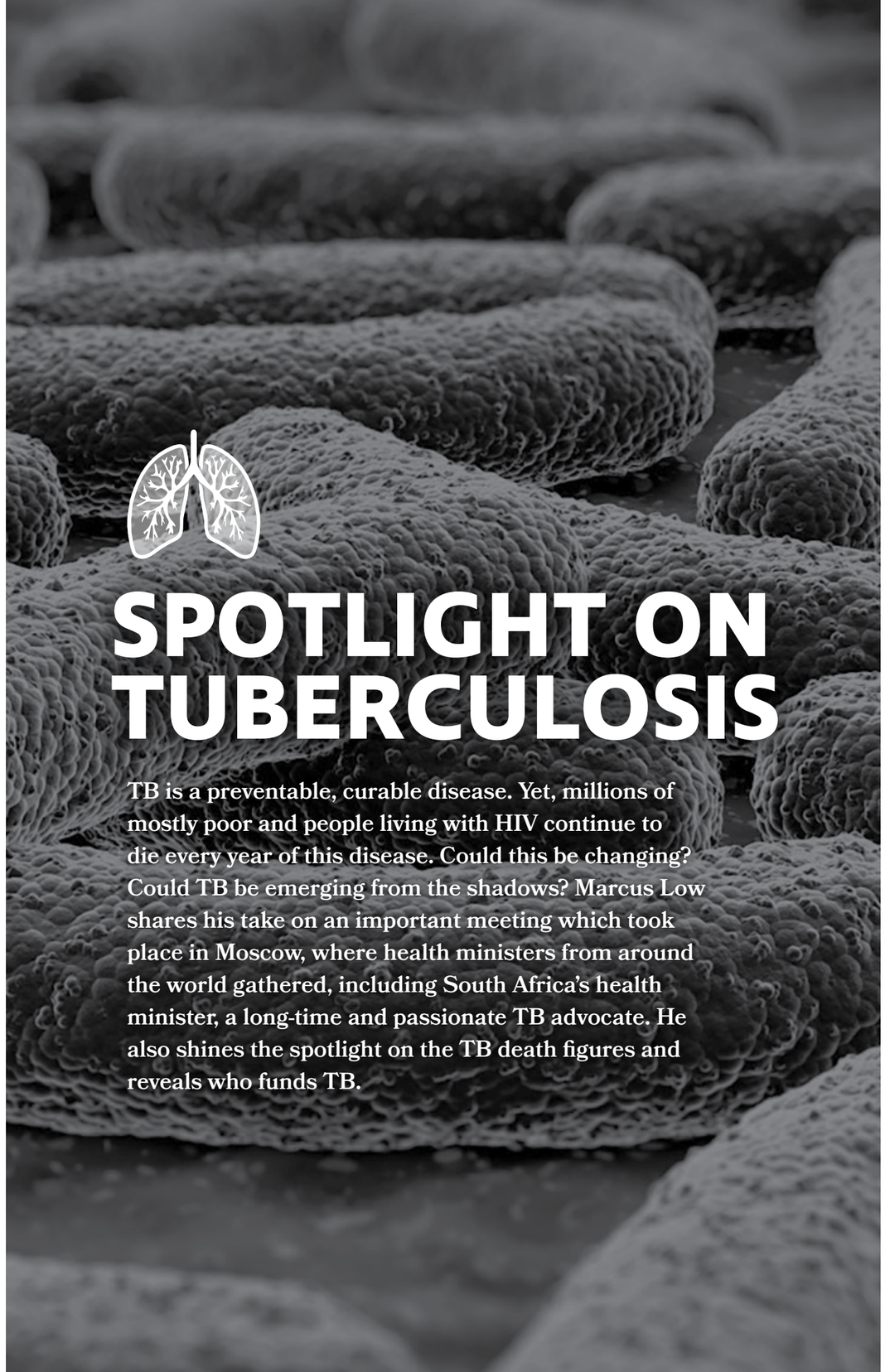
My decision to take PrEP almost broke my relationship with my boyfriend. He works in the north of KwaZulu-Natal, and we do not see each other often. He felt that my decision to take PrEP was motivated by a lack of trust in him. He wanted to leave me, and also accused me of cheating on him, saying that was the reason I'd decided to take the pill. After several arguments trying to explain to him why I'd decided to take PrEP, he went to a pharmacy to do blood tests, including an HIV test. He told me that he was 'clean'. I continued to take PrEP.

I must say, it wasn't easy in the beginning. Taking a pill when you are not sick is not child's play. It doesn't help that I suffered mild side effects – nausea, and a bit of dizziness – but they all subsided within a few days. I started taking PrEP during my exam preparations, so I used to take it every day at 21h00. Now that I have finished writing, 21h00 is no longer convenient for me. I take it earlier now.

A lot of my peers at university would benefit from PrEP. Most of them are dating celebrities, or guys who have money. I imagine some of them think they are 'exclusive', but this would be a lie. Though if CAPRISA didn't provide PrEP through its study clinic, and I had to pay for it, I wouldn't have considered it. I already have competing needs – buying PrEP with my financial aid money would be the last thing on my mind. The government should provide PrEP to everyone who needs it.

*Nomnotho Ntsele (20) is a second-year student at the Durban University of Technology. She also volunteers as a peer educator.

A lot of my peers at university would benefit from PrEP. Most of them are dating celebrities, or guys who have money. I imagine some of them think they are 'exclusive', but this would be a lie.



SPOTLIGHT ON TUBERCULOSIS

TB is a preventable, curable disease. Yet, millions of mostly poor and people living with HIV continue to die every year of this disease. Could this be changing? Could TB be emerging from the shadows? Marcus Low shares his take on an important meeting which took place in Moscow, where health ministers from around the world gathered, including South Africa's health minister, a long-time and passionate TB advocate. He also shines the spotlight on the TB death figures and reveals who funds TB.

SPOTLIGHT ON TB

Moment of truth for global TB response

Marcus Low, Spotlight

On Thursday 16 November 2017, Russian president Vladimir Putin told a hall full of health ministers in Moscow that TB is a "serious problem", and said, "I am confident that the only way we can stand up against this truly global threat is if we join forces." Over the next day and a half, the meeting at which President Putin was speaking – the first World Health Organisation (WHO) Global Ministerial Conference: Ending Tuberculosis in the Sustainable Development Era – positively resonated with such talk of the "urgency" of the TB crisis, and calls to "work together".

Yet one of the lessons one learns when working on TB is that whether it concerns financing, health-system reform or political will, the difference between what is said and what is done is often depressingly stark. Even as President Putin was reading his speech, many people in his own country still do not have access to a state-of-the-art diagnostic test that most experts agree should be a critical part of any country's TB response.

This gap between what is said on the international stage and what is done back home will have to close if meetings such as these are to have any impact on the actual treatment and care received by people with TB. The somewhat toothless declaration coming out of this week's meeting may generally say the right kind of things, but governments steered clear of making any firm and binding commitments. And without firm and binding commitments, it is hard to see how such declarations can have any real impact in a world of shrinking health budgets and many competing priorities.

Even so, the process heading into the Ministerial Meeting and onward to the September 2018 United Nations (UN) High-Level Meeting (HLM) on TB presents a rare moment of political opportunity to improve the often mediocre global response to TB. There is a kind of weary optimism among people working on TB – weary because of an underlying fatalism that seems to permeate much of the TB world; optimism because at last there is a reason to hope for substantially more political will, together with all the resources that entails.

How will the BRICS fund their plans?

Together with Putin's appearance, the establishment of a BRICS Research Network is probably the most concrete piece of good news from the meeting. Research cooperation between the BRICS (who together have around 40% of the world's TB cases) suggests that these governments may be willing to start shouldering more responsibility and investing in domestic research capacity. It is also indirect evidence of the failure of such research cooperation processes that have come through the WHO – where wealthy countries such as the United States have managed to scupper good ideas such as a binding R&D treaty. That the BRICS nations are taking the initiative is great news.

One concern is that the deliberations behind the BRICS TB Research Network to date have been relatively insular. As a next step, the negotiators – now involving the foreign ministries of each country – should reach out to civil society, and make the work of the network as transparent as possible. One of the network's priorities will be to "develop innovative mechanisms for R&D", guided by "principles of affordability, efficiency, equity, and effectiveness". Given the potential influence of industry lobbies, civil-society input may be needed to ensure these values are not lost along the way.

As with R&D more broadly, the true test of this network will be whether or not governments will put up the money. An unfunded network will offer only marginal benefits, and not the major innovations we need for TB. Extracting money from already stretched austerity budgets will be difficult, which means it will probably have to be found elsewhere. The idea of approaching the BRICS Bank was mentioned – other possibilities include sin taxes, or even financial-transaction taxes.

TB research grossly underfunded

That money for TB research is a problem is borne out by a recent report showing that total global investment in TB research was only around $726 million in 2016. The report, published by the Treatment Action Group (TAG), showed an increase over 2015 levels, but emphasised that it is still only around a third of the annual $2bn in total global investment that the WHO's End TB Plan estimates is needed per year. For some context, the United States military budget alone is set to rise by $54 billion in 2018, to around $600 billion.

The power of TB R&D as a critical indicator, when compared to the long laundry list of issues cited in the Moscow Declaration, is that it can be measured precisely. As such, it provides probably the clearest test we have of political will. If all the world's governments cannot even scrape together $2bn per year for a disease that kills around 1.7 million people a year, then the idealistic language of the ministerial declaration, and the declaration that will come out of next year's UN HLM on TB, will clearly be empty rhetoric – and perhaps worse than empty rhetoric; a kind of rhetoric that loudly proclaims to help the poor, but when the time comes, does nothing.

How much should countries contribute?

While the WHO's estimate that we need around $2bn per year for TB research is a good starting point, there are obvious differences regarding who should contribute how much. As with cutting greenhouse gas emissions, countries will differ on who is responsible for what, and on what is fair. It seems likely that a system perceived to be fair will be required if countries are to buy in or to sign up to binding funding commitments.

This problem has now been satisfactorily solved – at least in my view – by a new set of country-specific targets published by TAG. TAG suggests that each of the high-TB-burden countries and the G20 should invest 0.1% of their Gross Domestic Expenditure on R&D (GERD) in TB research. This means, by definition, that less is asked of countries that invest less in R&D, and more of countries that invest more – something that builds a degree of fairness and realism into the targets.

As with any targets, these are imperfect. It may or may not be a good idea to ask more of high-burden countries than is indicated in these targets. Perhaps there should be greater focus on increasing overall R&D spending, rather than shifting existing R&D funds to TB. When one looks at the actual targets, though, most of these criticisms fall away. Most countries will be asked to invest more (currently, only South Africa and Norway meet the targets) – but in almost all cases, the asks are realistic, given the threat and seriousness of TB. The 0.1% of GERD target also has the benefit of being simple. More complicated formulas taking into account TB burden, GDP, and GERD could be developed – but adding such complexity would make the targets more opaque.

Kicking it upstairs

In a rousing speech at the opening of the meeting, South Africa's Minister of Health, Dr Aaron Motsoaledi, said: "We must come up with innovative research and development models, such as The Life Prize – formerly known as the '3P' project – which delinks the cost of R&D from the final cost of medicines." It was disappointing that, apart from strong interventions by Motsoaledi and South Africa's Director General of Health, Precious Matsoso, The Life Prize and delinkage did not get more traction at the conference – given that The Life Prize (in its specificity) and delinkage (with its intellectual framework) are some of the best responses we have to the partial market failure of TB medicines and diagnostics, where patent protection has proven insufficient incentive to drive innovation. In his understanding of how increased R&D can best play out in the real world, Motsoaledi was a step ahead of most other speakers.

He was also clearer than most about the politics of the process, heading toward the UN HLM. He was unequivocal that heads of states must now take responsibility, and give ministers their "marching orders" in the fight against TB. He is correct.

At the opening of the ministerial meeting, President Putin said: "Another important success factor is to step up scientific tuberculosis research and develop effective diagnostic tools, vaccines and medicines, including those aimed at treating resistant forms of tuberculosis. In this regard, I believe that the initiative of the BRICS countries to create a network to study tuberculosis is very important."

No doubt many similar things will be said by other world leaders in the next 10 months, and at the 2018 UN HLM on TB. Yet, behind the words, hard cash and hard indicators such as investment in R&D will tell us whether our world leaders mean what they say; whether President Putin is serious about TB; whether the emperor is wearing any clothes.

SPOTLIGHT ON TB

Who funds TB research?

Marcus Low, Spotlight

Investment in TB research can be measured in many ways. The most obvious way is simply to look at who gives the most money for TB research. The country that gives the most, by far, is the United States – which gives more money than all other countries combined.

"South Africa ranks first when its spending on TB R&D is judged relative to its GDP and GERD; however, this is largely a function of South Africa's lower GDP and R&D expenditures, compared to other countries that report data. The absolute amount of money South Africa gives to TB research is still low – only $6.5 million last year – and most goes to a handful of universities and academic medical centres.

"Given the burden of TB in South Africa, its significant clinical trials capacity, and the depth of its scientific talent, there is ample room for South Africa to increase its contributions to TB research. In addition to supporting domestic researchers through grant funding, South Africa should explore innovative ways to finance and incentivise TB research, including co-financing for regional and global initiatives such as The Life Prize or the BRICS TB Research Network."

Mike Frick, author of the TAG TB R&D Report

Of the $726 million invested in TB research and development (R&D) in 2016, 66% was invested by governments, 20% by philanthropic organisations, 11% by industry, and 3% by multilateral entities. Together, the United States National Institutes for Health (NIH) and the Gates Foundation contributed half of global investment in TB R&D. Many pharmaceutical companies do not invest in TB at all; and the few that do, invest relatively small amounts.

The top 10 countries in terms of absolute investment in TB R&D were:

1. United States $316 471 566
2. United Kingdom $27 575 390
3. European Union $23 575 253
4. Canada $16 898 180
5. Germany $14 820 938
6. India $14 768 283
7. South Korea $12 359 135
8. The Netherlands $9 858 859
9. Australia $9 489 424
10. South Africa $6 465 746

While a new BRICS TB Research Network was announced recently, of the five BRICS countries, only India and South Africa are in the top 10 in terms of absolute investment in TB R&D. Large developing economies such as China, Russia, Indonesia and Brazil make only very modest investments in TB R&D. Among wealthy countries, the very low investment made by France, Japan, Italy and Spain is notable.

SA top on two important measures

In the latest TAG R&D report, South Africa is ranked number one on two important measures of investment in TB R&D: percentage of GDP and percentage of GERD (explained below). In terms of the absolute investment in TB R&D, South Africa ranked 10th, with $6.5 million (around R90 million) invested in 2016. Whichever measure you use, South Africa invests more than most other countries with high TB burdens.

Yet, even with South Africa's relatively high levels of investment in TB R&D, many of our researchers are still dependent on funding from the United States government to do their research. The United States invests almost 50 times as much as South Africa in TB R&D.

Percentage of GDP

Because countries have different-sized economies and different levels of development, simply looking at who gives the most money is not always a fair comparison. One alternative is to see what percentage of a country's GDP is spent on TB R&D. GDP, or Gross Domestic Product, is the total value of everything produced by all the people and companies in a country.

The top 10 countries in terms of percentage of GDP invested in TB R&D are:

COUNTRY	TB R&D FUNDING 2016	GDP 2016 (USD MILLIONS)	TB R&D EXPENDITURE AS PERCENTAGE OF GDP RANK ORDER
South Africa	$6 465 746	$294 841	1
United States	$316 471 566	$18 569 100	2
Norway	$5 503 497	$370 557	3
The Netherlands	$9 858 859	$770 845	4
Canada	$16 898 180	$1 529 760	5
United Kingdom	$27 575 390	$2 618 886	6
Switzerland	$5 938 196	$659 827	7
South Korea	$12 359 135	$1 411 246	8
Australia	$9 489 424	$1 204 616	9
India	$14 768 283	$2 263 523	10

Percentage of GERD

Another option is to look at what percentage of all the money invested in R&D in a country is invested specifically in TB R&D. This total investment in R&D in a country is called GERD, or Gross Domestic Expenditure on R&D.

The top 10 countries in terms of percentage of GERD invested in TB R&D are:

COUNTRY	TB R&D FUNDING 2016	AVERAGE ANNUAL GERD 2010–2015	GERD CALCULATION	TB R&D EXPENDITURE AS PERCENTAGE OF GERD RANK ORDER
South Africa	$6 465 746	$4 718 475 774	0,14%	1
Norway	$5 503 497	$5 441 716 100	0,10%	2
United States	$316 471 566	$452 804 833 333	0,07%	3
United Kingdom	$27 575 390	$41 157 956 465	0,07%	4
Canada	$16 898 180	$25 773 702 491	0,07%	5
The Netherlands	$9 858 859	$15 342 022 220	0,06%	6
Australia	$9 489 424	$21 554 008 715	0,04%	7
Switzerland	$5 938 196	$13 669 878 710	0,04%	8
The Philippines	$302 178	$762 079 532	0,04%	9
New Zealand	$679 649	$1 811 948 569	0,04%	10

TAG calculated that in order to meet the WHO End TB Plan's target of $2 billion per year for TB R&D, all high-burden and G20 countries must invest 0.1% of GERD in TB R&D. Currently, the only two countries to meet this target are South Africa and Norway.

The figures in this article are taken from the Treatment Action Group report 'The Ascent Begins: Tuberculosis Research Funding Trends, 2005-2016', published in November 2017. Find the full report at www.TreatmentActionGroup.org/TB

1.7 million TB deaths in 2016

Marcus Low, Spotlight

In 2016, almost 1.7 million people across the globe, and over 120 000 in South Africa, died of TB. We unpack these and other findings from the World Health Organisation's latest World TB Report.

Almost 1.7 million people died of TB in 2016, according to the World Health Organisation's latest World TB Report, published early in November. This means that TB remains the leading cause of death from a single infectious agent. Of the almost 1.7 million deaths, 1.3 million were of people who did not have HIV, and 374 000 were of people who were living with HIV.

India remains the epicentre of the global TB epidemic, with 26% of worldwide TB deaths in 2016. India also had the most TB cases, followed by Indonesia, China, the Philippines and Pakistan.

According to the report, an estimated 124 000 people in South Africa died of TB in 2016 – of these, 101 000 had HIV, and 23 000 did not.

10.4 million fell ill with TB

The report also found that in 2016, an estimated 10.4 million people around the world fell ill with TB. Of these people, 90% were adults, 65% were male, and 10% were people living with HIV. Globally, 83% of people with TB are treated successfully.

In South Africa there were around 438 000 new TB cases in 2016. Of these, 182 000 were in women and 256 000 in men. This means that around 58% of new TB cases were in men; thus, while still skewed toward men, the TB epidemic in South Africa is less skewed than elsewhere – probably as result of South Africa's high HIV rates, and the fact that HIV rates are higher in women than in men.

The DR-TB epidemic

In 2016, an estimated 600 000 people around the world newly acquired TB resistant to rifampicin (one of the most effective TB drugs). Of these, 490 000 people's TB was also resistant to another critical TB drug, called isoniazid (TB that is resistant to these two drugs is called multi-drug-resistant TB, or MDR-TB). Almost half (47%) of these cases were in South Africa's BRICS partners: India, China and the Russian Federation.

According to the report, South Africa had around 19 000 cases of MDR- or rifampicin-resistant (RR) TB. Only around 11 000 of these people received treatment. Disappointing as that is, the global picture is even worse – a total of 129 689 people were started on treatment, a small increase from 125 629 in 2015. This figure amounts to only 22% of the people who need treatment. And for those lucky enough to receive treatment for MDR- or RR-TB, unfortunately, treatment success remains low, at a miserly 54% globally.

South Africa remains a leader in the provision of TB-preventive therapy. Globally, around 940 000 people newly started on antiretroviral therapy were also provided with TB-preventive therapy. Of these people, 41% (about 385 000) were in South Africa. For this, the South African National Department of Health deserves credit.

Not good enough?

The report found that the global number of TB deaths is falling by around 3% per year, and the global number of new infections by about 2%. Currently, about 16% of people who get TB die of the disease. To meet the targets of the WHO's End TB Strategy, this number must drop to 10% by 2020. The death rate and the rate of new infections will both have to drop by about 5% per year by 2020. The End TB Strategy aims for a 90% reduction in TB deaths and an 80% reduction in new infections per year by 2030 (compared to 2015).

The report goes on to recognise that "the WHO Global Ministerial Conference on ending TB in the SDG era in November 2017 and the first UN General Assembly high-level meeting on TB in 2018 provide a historic opportunity to galvanise the political commitment needed to step up the battle against TB, and put the world and individual countries on the path to ending the TB epidemic".

While not explicitly stated in the report, one critical test of political commitment in these multinational forums will be the concrete financial investments governments do or do not make in TB research and development (R&D). Currently, global annual investment in TB R&D is only around a third of the annual $2bn that the WHO estimates is needed. According to the report, "Increased investment in research and development is needed for there to be any chance of achieving the technological breakthroughs needed by 2025."

"Overall, the latest picture is one of a still-high burden of disease, and progress that is not fast enough to reach targets or to make major headway in closing persistent gaps." – 2017 WHO World TB Report

Estimated epidemiological burden of TB in 2016 for 30 high TB burden countries, WHO regions and globally. Numbers in thousands.

	POPULATION	HIV-NEGATIVE TB MORTALITY		HIV-POSITIVE TB MORTALITY		INCIDENCE		HIV-POSITIVE TB INCIDENCE	
		BEST ESTIMATE	UNCERTAINTY INTERVAL	BEST ESTIMATE	UNCERTAINTY INTERVAL	BEST ESTIMATE	UNCERTAINTY INTERVAL	BEST ESTIMATE	UNCERTAINTY INTERVAL
Angola	29 000	18	10–29	6.9	3.4–12	107	66–156	18	8.5–30
Bangladesh	163 000	66	43–94	0.18	0.09–0.30	360	262–474	0.50	0.25–0.84
Brazil	208 000	5.4	4.9–5.9	1.9	1.4–2.4	87	74–100	11	9.1–13
Cambodia	16 000	3.2	2.1–4.4	0.45	0.29–0.66	54	35–78	1.3	0.85–1.9
Central African Republic	5 000	2.7	1.5–4.2	2.5	1.3–4.0	19	12–27	6.2	3.3–9.9
China	1 404 000	50	34–70	1.8	0.7–3.4	895	766–1 030	11	6.9–15
Congo	5 000	3.1	1.7–4.8	2.1	1.1–3.4	19	12–28	5.1	2.6–8.4
DPR Korea	25 000	11	6.8–16	0.05	0.02–0.09	130	113–148	0.28	0.14–0.46
DR Congo	79 000	53	31–80	8.5	4.0–15	254	165–363	20	13–29
Ethiopia	102 000	26	16–37	4.0	2.7–5.4	182	128–245	14	9.6–19
India[c]	1 324 000	423	324–534	12	6.6–19	2 790	1 440–4 570	87	56–125
Indonesia	261 000	110	75–152	13	6.2–23	1 020	660–1 460	45	21–78
Kenya	48 000	29	16–45	24	14–36	169	103–250	53	32–79
Lesotho	2 000	1.1	0.56–1.8	5.2	3.3–7.7	16	10–23	12	7.3–17
Liberia	5 000	2.8	1.6–4.2	0.96	0.60–1.4	14	9.2–20	2.2	1.4–3.2
Mozambique	29 000	22	13–33	33	20–48	159	103–227	72	46–104
Myanmar	53 000	25	16–35	4.9	3.5–6.6	191	141–249	18	13–24
Namibia	2 000	0.75	0.48–1.1	0.87	0.61–1.2	11	8.5–14	4.2	2.7–6.0
Nigeria	186 000	115	67–176	39	23–58	407	266–579	63	40–93
Pakistan	193 000	44	34–55	2.1	0.98–3.6	518	335–741	6.9	3.2–12
Papua New Guinea	8 000	3.6	2.4–50	0.82	0.45–1.3	35	28–42	3.6	2.0–5.5
Philippines	103 000	22	22–22	0.30	<0.01–2.6	573	321–895	6.0	2.5–11
Russian Federation	144 000	12	11–12	1.7	0.85–2.7	94	61–135	18	12–26
Sierra Leone	7 000	3.4	2.0–5.2	1.0	0.66–1.5	22	14–32	3.1	2.0–4.5
South Africa	56 000	23	17–29	101	67–142	438	304–595	258	176–355
Thailand	69 000	8.6	7.2–10	3.9	2.3–5.9	119	70–180	10	6.1–16
UR Tanzania	56 000	28	13–50	27	12–46	160	75–275	54	35–78
Viet Nam	95 000	13	8.4–18	0.85	0.63–1.1	126	103–151	4.2	3.4–5.1
Zambia	17 000	4.8	2.8–7.3	12	7.9–18	62	40–89	36	23–52
Zimbabwe	16 000	1.2	0.71–1.7	4.4	3.0–6.1	34	24–44	23	15–32
High TB burden countries	4 710 000	1 130	998–1 270	317	268–369	9 060	7 450–10 800	866	755–986
Africa	1 020 000	417	351–488	320	272–372	2 590	2 310–2 900	764	660–876
The Americas	996 000	17	16–18	6.2	5.6–6.9	274	255–294	30	28–33
Eastern Mediterranean	669 000	82	69–95	3.0	1.8–4.5	766	573–985	9.9	5.9–15
Europe	916 000	26	25–27	5.1	3.9–6.4	290	251–333	34	26–42
South-East Asia	1 950 000	652	542–772	35	25–46	4 670	3 190–6 440	163	120–211
Western Pacific	1 890 000	103	85–123	5.0	3.0–7.3	1 800	1 500–2 130	29	23–36
GLOBAL	7 440 000	1 300	1 160–1 440	374	325–427	10 400	8 770–12 200	1 030	915–1 150

[a] Numbers shown to two significant figures if under 100 and to three significant figures otherwise.
[b] Deaths among HIV-positive TB cases are classified as HIV deaths according to ICD-10.
[c] Estimates of TB incidence and mortality for India are interim in nature, pending results from the national TB prevalence survey planned for 2018/2019.

Source: 2017 WHO World TB Report

Let's make AIDS councils work

Vuyokazi Gonyela, SECTION27

Every province and district should have an AIDS council. These AIDS councils are supposed to bring everyone (government, organised labour, business, civil society) together to jointly plot our response to HIV, TB and STIs.

Provincial AIDS Councils (PACs) should be chaired by Premiers, and District AIDS Councils (DACs) by mayors. All councils should meet at least once a quarter – but many do not. If your DAC or PAC is not meeting, write to your Premier or mayor to urge them to organise and chair these meetings. Once we are at the meetings, it is up to us to use them to ensure we get an effective, non-corrupt response to HIV, TB and STIs in our provinces or districts.

Tell us about your PAC or DAC experiences. Send an e-mail to info@spotlightnsp.co.za.

Seven questions to ask at your PAC

Not sure what to say at Provincial AIDS Council meetings? Here are some ideas for questions you could ask.

1. South Africa's new NSP envisages an ambitious new HIV Counselling and Testing Campaign. When are we starting to implement this HCT campaign in our province?

Here is the relevant part of the NSP, if you want to quote it in the meeting:

"A new national HIV testing effort to find the remaining people who don't know their status and those who become newly infected will be strategically focused on optimising testing yield. Testing will be decentralised, and expanded testing services will be delivered in and outside health facilities, e.g. in workplaces and community settings. Specific efforts will be made to close testing gaps for men, children, adolescents, young people, key and vulnerable populations, and other groups who are not currently accessing HIV testing at sufficient levels.

"The importance of at least annual HIV testing will be emphasised, especially for young people. Self-screening will be rolled out as part of the strategy to expand HIV testing, and to close testing gaps. A major push will be made to ensure 100% birth-testing of newborns exposed to HIV, and of provider-initiated counselling of mothers and testing for all children up to 18 months to identify those who have acquired HIV through breastfeeding. All children of HIV-positive parents will be tested for HIV. Every person tested for HIV will also be screened for other STIs, as well as for TB."

2. The new NSP says that the tracing of TB contacts must be prioritised; and that it envisages intensified TB case-finding in key populations, "including household contacts of people with TB disease, healthcare workers, inmates, and people living in informal settlements." What are we doing to step up contact tracing and active case-finding in our province?

Here is the relevant part of the NSP, if you want to quote it in the meeting:

"Every person who is tested for HIV must also be screened for TB, as must all TB contacts. Tracing of TB contacts is especially urgent for DR-TB, and will be prioritised. This Plan envisages intensified TB case-finding in key populations, including household contacts of people with TB disease, healthcare workers, inmates, and people living in informal settlements. People with diabetes and every child contact of an adult TB patient will be screened. All patients suspected to have TB will receive appropriate diagnostics, including GeneXpert MTB/RIF as an initial diagnostic, and rapid confirmation of results."

3. The NSP sets important national targets. What are our provincial targets relating to reducing new HIV infections and reducing new cases of TB?

Setting provincial targets is essential if we wish to create greater accountability in our province. It also helps focus and direct the work that needs to happen in the province. Yet most provinces do not have targets. Getting your province to set ambitious and concrete targets will be an important achievement.

Some key national targets in the NSP for which we require provincial equivalents are as follows:

- Reduce new HIV infections to under 100 000 per year by 2022.
- Reduce TB incidence by at least 30%, from 834/100 000 population in 2015 to fewer than 584/100 000 by 2022.
- 10 million people should receive an HIV test every year.

4. Can the Department of Health please provide us with detailed, up-to-date statistics for our province on our progress towards the 90-90-90 targets for HIV and the 90-90-90 targets for TB?

The 90-90-90 targets for HIV and TB are at the centre of the NSP. To create local accountability, and to identify areas that need work, we should track progress against these targets within our provinces, not only at national level. As members of AIDS councils, you have a right to this information.

For HIV, the 90-90-90 targets for provinces are:

- By 2020, 90% of all people in the province living with HIV will know their HIV status.
- By 2020, 90% of all people in the province with diagnosed HIV infection will receive sustained antiretroviral therapy.
- By 2020, 90% of all people in the province receiving antiretroviral therapy will have viral suppression.

For TB, the 90-90-90 targets for provinces are:

- By 2020, 90% of vulnerable groups in the province will have been screened for TB.
- By 2020, 90% of people in the province with TB will have been diagnosed and started on treatment.
- By 2020, 90% of people in the province on treatment will have been successfully treated.

5. What is the status of our provincial implementation plan (PIP)?

The PIPs may sound boring, but they are the plans that must make the goals and broad strategies of the NSP a reality in the communities across our provinces. By engaging in these plans, we can help improve the HIV and TB response in our provinces. Developing these plans is some of the most important work that AIDS councils will do. Once they have been developed, adapting these plans over time and monitoring their implementation will be just as important. In short, if you are on a PAC, part of your responsibility is to know exactly what is going on with your PIP.

In addition to the above question, here are some follow-up questions you could ask:

a. Is the implementation of the PIP in our province fully costed?
b. Where is the money going to come from to implement our PIP?
c. Do we have the human resources to implement our PIP?

6. Can the Department of Health please provide us with detailed statistics on the best- and worst-performing districts in our province?

'Best' and 'worst' can be measured in different ways. For that reason, it might be worth asking for more specific indicators of how districts are performing. Here are some examples:

a. What are the viral load coverage rates for each of the districts in our province? (Viral load coverage tells you whether all people on HIV treatment are getting viral load tests, as they are supposed to. If a district has a low viral load coverage rate, then you know there is a problem in that district, because people are not getting the tests that they are supposed to get.)
b. What are the districts in our province with the most medicine stock-outs?
c. What are the TB treatment success rates for each of the districts in our province?

Six questions to ask at your DAC

Not sure what to say at District AIDS Council meetings? Here are some ideas for questions you could ask.

1. South Africa's new NSP envisages an ambitious new HIV Counselling and Testing Campaign. When are we starting to implement this HCT campaign in our district?

Here is the relevant part of the NSP, if you want to quote it in the meeting:

"A new national HIV testing effort to find the remaining people who don't know their status and those who become newly infected will be strategically focused on optimising testing yield. Testing will be decentralised, and expanded testing services will be delivered in and outside health facilities, e.g. in workplaces and community settings. Specific efforts will be made to close testing gaps for men, children, adolescents, young people, key and vulnerable populations, and other groups who are not currently accessing HIV testing at sufficient levels.

"The importance of at least annual HIV testing will be emphasised, especially for young people. Self-screening will be rolled out as part of the strategy to expand HIV testing, and to close testing gaps. A major push will be made to ensure 100% birth-testing of newborns exposed to HIV, and of provider-initiated counselling of mothers and testing for all children up to 18 months, to identify those who have acquired HIV through breastfeeding. All children of HIV-positive parents will be tested for HIV. Every person tested for HIV will also be screened for other STIs, as well as for TB."

2. The new NSP says that the tracing of TB contacts must be prioritised; it envisages intensified TB case-finding in key populations, "including household contacts of people with TB disease, healthcare workers, inmates, and people living in informal settlements." What are we doing to step up contact tracing and active case-finding in our province?

Here is the relevant part of the NSP, if you want to quote it in the meeting:

"Every person who is tested for HIV must also be screened for TB, as must all TB contacts. Tracing of TB contacts is especially urgent for DR-TB, and will be prioritised. This Plan envisages intensified TB case-finding in key populations, including household contacts of people with TB disease, healthcare workers, inmates, and people living in informal settlements. People with diabetes and every child contact of an adult TB patient will be screened. All patients suspected to have TB will receive appropriate diagnostics, including GeneXpert MTB/RIF as an initial diagnostic, and rapid confirmation of results."

3. The NSP sets important national targets. What are our district targets relating to reducing new HIV infections and reducing new cases of TB?

Setting district and provincial targets is essential if we wish to create greater accountability in our districts and provinces. It also helps focus and direct the work that needs to happen at district level. Yet most districts do not have targets. Getting your district to set ambitious and concrete targets will be an important achievement.

Some key national targets in the NSP for which we require district and provincial equivalents are as follows:

- Reduce new HIV infections to under 100 000 per year by 2022.
- Reduce TB incidence by at least 30%, from 834/100 000 population in 2015 to fewer than 584/100 000 by 2022.
- 10 million people should receive an HIV test every year.

4. Can the Department of Health please provide us with detailed, up-to-date statistics on our progress towards the 90-90-90 targets for HIV and the 90-90-90 targets for TB in our district?

The 90-90-90 targets for HIV and TB are at the centre of the NSP. To create local accountability, and to identify areas that need work, we must track progress against these targets within our districts and provinces, and not only at national level. As members of AIDS councils, you have a right to this information.

For HIV, the 90-90-90 targets for districts are:

- By 2020, 90% of all people in the district living with HIV will know their HIV status.
- By 2020, 90% of all people in the district with diagnosed HIV infection will receive sustained antiretroviral therapy.
- By 2020, 90% of all people in the district receiving antiretroviral therapy will have viral suppression.

For TB, the 90-90-90 targets for districts are:

- By 2020, 90% of vulnerable groups in the district will have been screened for TB.
- By 2020, 90% of people in the district with TB will have been diagnosed and started on treatment.
- By 2020, 90% of people in the district on treatment will have been successfully treated.

5. What is the status of our provincial implementation plan (PIP)? And if we have a District Implementation Plan (DIP), what is the status of that?

The PIPs and DIPs may sound boring, but they are the plans that must make the goals and broad strategies of the NSP a reality in our communities. By engaging in these plans, we can help improve the HIV and TB response. Developing these plans is some of the most important work that AIDS councils will do. Once they have been developed, adapting these plans over time and monitoring their implementation will be just as important. In short, if you are on a DAC or PAC, part of your responsibility is to know exactly what is going on with your DIP and/or PIP.

In addition to the above question, here are some follow-up questions you could ask:

a. Is the implementation of the PIP and DIP in our district fully costed?
b. Where is the money going to come from to implement our PIP (or DIP)?
c. Do we have the human resources to implement the PIP (Or DIP)?

6. Can the Department of Health please provide us with detailed statistics on the best- and worst-performing clinics in our district?

'Best' and 'worst' can be measured in different ways. For that reason, it might be worth asking for more specific indicators of how clinics are performing. Here are some examples :

a. What are the five clinics in our district with the lowest viral load coverage rate? (Viral load coverage tells you whether all people on HIV treatment are getting viral load tests, as they are supposed to. If a clinic has a low viral load coverage rate, then you know there is a problem at that clinic, because people are not getting the tests that they are supposed to get.)
b. What are the five clinics in our district with the most medicine stock-outs?
c. What are the five clinics in our district with the worst TB treatment success rates?

Overdue IP reform process crucial for healthcare in South Africa

Luvo Nelani and Zain Rizvi, SECTION27

On 17 November 2017, at the University of the Witwatersrand, Nobel Laureate Joseph Stiglitz gave a lecture to a standing-room-only crowd. The lecture, entitled Intellectual Property and Societal Welfare, came as the Department of Trade and Industry (DTI) moves forward on reforms to South Africa's intellectual property (IP) regime.

In August, the DTI published a draft intellectual-property policy that contains a number of new measures to protect public health.

One of the world's most influential economists, Stiglitz lauded the proposed IP reforms, noting that they reflected South Africa's developmental needs. He urged the government to set an important precedent for other countries, and resist pressure to abandon the reforms.

In 2014, the South African media revealed a $600 000 plot by the US and European pharmaceutical industry to interfere with South Africa's IP reform process. Reportedly, US pressure then delayed the policy.

Stiglitz, who once served as the top economist in the US government, pointed out examples of US hypocrisy. The US government has previously considered using the flexibilities permitted by international law to help its own citizens when necessary, but derails the efforts of other countries to do the same. Stiglitz noted how, at the peak of the anthrax crisis in 2001, the US government threatened to issue compulsory licences to increase access to an antibiotic.

To laughter from the audience, Stiglitz warned that South Africa faced another challenge in the current US President, Donald Trump. His recommendation: "Don't normalise him – don't give him concessions you wouldn't give [another] person."

Stiglitz also forcefully dispelled the notion that IP drives innovation. He highlighted the considerable evidence that poorly designed IP regimes may in fact hamper innovation, by restricting access to knowledge. In the most memorable anecdote of the night, he recalled a conversation with his fellow Nobel Laureates – acclaimed for their breakthrough advances in science – about the role of IP. Not one of them, he said, was ever motivated by IP.

Designing an appropriate IP regime is vital, Stiglitz noted, because it could have significant consequences for public health. He described how pharmaceutical companies use a range of tactics to exploit the IP system. One example is 'evergreening' – a method used by manufacturers to get an additional 20 years of patent protection on existing medicines through minor innovations, effectively blocking generic versions and keeping prices high.

The Professor of Economics was later in the evening in conversation with Dr Malebakeng Forere, an academic from the University, Marumo Nkomo from the DTI, a co-author of his recently published paper Innovation, Intellectual Property and Development, Arjun Jayadev and SECTION27. Umunyana Rugege, an attorney at SECTION27, noted that many of the reforms envisaged by Stiglitz were necessary, given South Africa's constitutional obligations to increase access to healthcare services.

Since 2011, SECTION27 has been part of a coalition calling for South Africa to reform its patent laws. Known as the 'Fix the Patent Laws' campaign, it has been advocating for an IP policy that prioritises public health and increases access to medicines.

On 24 October, Fix the Patent Laws launched a report that analysed patent barriers to cancer treatment access in South Africa. The report found that only seven of 24 important cancer drugs were available in the public health system. Ten medicines unavailable in the public sector – most probably due to their cost – are available in India for a fraction of the private price offered in South Africa.

The report confirmed earlier research showing that South Africa grants large numbers of secondary patents on medicines often rejected in other countries – a critical factor driving the vast price differences between the same medicines in South Africa and India.

The Stiglitz lecture and later discussion served as an important reminder of the urgency of the IP reform process. Now, the DTI must urgently finalise and implement the draft intellectual property policy. Only then will access to medicines become a reality – and not simply a legal promise – for thousands of people in South Africa.

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