

**MEETING THE CHALLENGES OF HIV TREATMENT AND PREVENTION
THROUGH INDEPENDENT MOBILISATION AND WORK THROUGH
THE SA NATIONAL AIDS COUNCIL (SANAC)**

– A TEN POINT AGENDA FOR SAVING AND BETTERING LIVES

October 2010

We the undersigned are civil society organisations and trade unions committed to working independently and through SANAC to strengthen the HIV response and achieve the goals of the NSP. We believe that sustained pressure through civil society activism that focuses on our human right to health was necessary in the past and is still necessary.

We have produced this statement against the backdrop of South Africa's failure to make progress against key Millennium Development Goals (MDGs).

South Africa is among the world's ten worst performing countries for infant, child and maternal health outcomes. We are failing against at least six of the eight MDGs. High HIV related morbidity and mortality is responsible for the poor and deteriorating outcomes of half of these indicators.

Below we set out our both our demands and our responsibilities.

1. We Demand Sustained Political Leadership and Engagement from the Highest Level of Government on an effective and efficient HIV response!

We commend the leadership of the chairperson of SANAC, Deputy President Kgalema Motlanthe, and the efforts of the Minister of Health, Dr. Aaron Motsoaledi, to transform South Africa's HIV and TB response. We acknowledge the steps that have been taken by our country's leadership to move away from AIDS denialism and to begin to make the substantial investments into health and HIV that are necessary.

The HIV response costs South Africa approximately R17billion each year. We have a joint responsibility to ensure that this money leads to improved health outcomes – to reductions in the number of new HIV and TB infections, to reduced illness and death and improved life expectancy.

We welcome the climate of openness and cooperation with government and our greatly improved ability to work with government. We wasted much time in the 2000s fighting AIDS denialism and

¹ This statement was developed at an Activist Dialogue convened jointly by SECTION27 and HIVSA on 16 and 17 September 2010. All organisations who agree with its statements are encouraged to become signatories. To do so please contact Kate Paterson at paterson@section27.org.za

banging on the door asking for a seat at the table. Nonetheless civil society has a range of concerns which we will prioritise over the remaining period of the NSP (2007- 2011) and beyond.

We as civil society will:

- *Re-establish the Civil Society Co-ordinating and Monitoring Forum (CSCMF) to improve cooperation, coordination and our engagement with critical issues. The CSCMF is will aim to strengthen the accountability of civil society organisations as we cannot demand an accountable government if we are not accountable to our own constituencies. Co-ordination of the CSCMF will be rotated and it will meet quarterly.*

2. We demand a Unified Communications Strategy on HIV and TB Prevention!

Civil society agrees with the Minister of Health: Effective HIV prevention is a crucial priority. In this respect we are worried that we do not have a national HIV prevention roadmap or strategy. In particular we are concerned that:

- There has been no evaluation or report of the Khomanani programme, despite lingering allegations of mismanagement and corruption;
- That positive prevention programmes are non-existent and people with HIV not consulted or involved in prevention;
- That femidoms remain unaffordable and as a result largely unavailable;
- That the SABC is acting in a way that inhibit the dissemination of effective media on HIV prevention;
- That community care workers are not being systematically linked to the prevention programme, despite evidence from interventions such as the A-Plan on PMTCT that have demonstrated their value and potential.

That government continues to locate HIV prevention primarily within the department of health. HIV prevention should be a priority of all government departments, especially within the Social Cluster. We demand that SANAC and the Provincial AIDS Councils should be made responsible for coordinating joint government and civil society efforts to make HIV prevention effective.

Civil society has long advocated for a national rollout of voluntary medical male circumcision (VMMC). We applaud the Minister of Health, the King and Premier of KZN for their leadership on this matter. But the release of the national VMMC policy continues to be delayed and that there are no national guidelines to govern VMMC. We call on these to be released urgently.

This policy vacuum has led to the implementation of medical circumcision in KZN through the use of a medically dangerous device – the Tara Klamp. To roll out VMMC using a method that is dangerous to men threatens to undermine public confidence and acceptance of the VMMC. We therefore demand that the Deputy President and the Minister of Health intervene with utmost urgency to halt the use (and purchase) of the Tara Klamp until a VMMC policy based on sound medically proven procedures can be adopted nationally.

We as civil society:

- *Have appointed an expert task team to develop a draft HIV and TB prevention roadmap / strategy and a comprehensive joint national communications plan that we will present to SANAC and, in the interim, the Director General of the Department of Health;*

- *Commit to presenting this roadmap/ strategy to whomever Cabinet appoints to coordinate and manage HIV prevention on behalf of the Social Cluster;*
- *Will advocate that an effective communications campaign be funded from the nearly R90m that is within the 2010-2011 budget.*
- *Resolve to seek a meeting with the Board of the SABC and the Minister of Communications to demand that the SABC, as a public broadcaster, plays a full role in HIV prevention efforts and media campaigns.*

3. We Support the HIV Counselling and Testing (HCT) campaign – but implementation must be drastically improved!

We support the national HCT campaign. The targets are ambitious and seek to respond to HIV on a scale that is in keeping with the size of the epidemic and the number of people who needs care and treatment. The campaign is vital, but we are concerned at the quality of its implementation because:

- Research shows that in many clinics across SA HIV testing is being performed inappropriately and/or incorrectly.
- The campaign is badly co-ordinated, the quality of the reported data is poor and there is little effective oversight of its implementation.
- Health care workers are necessarily at the forefront of the campaign yet they express great frustration with poor communication from national and provincial health departments.
- Traditional health practitioners, who could be a vital cadre, have not been sufficiently included in the campaign.
- Lay counsellors (in ever growing pockets) who are at the core of the programme have not been paid stipends across all provinces for some months, along with other Community Care workers
- The SANAC Secretariat has been distracted from its mandate by managing the HCT Campaign Nerve Centre on behalf of the NDoH. Nerve centres at the national, provincial and district level should run by Departments of Health.
- We continue to receive reports of HIV testing without consent, coercion and breaches of confidentiality.

We call upon the National and Provincial Departments of Health and SANAC to:

- Improve communication to front-line health care workers and ensure that they are adequately informed and effectively trained.
- Improve data collection and the use of strategic information to monitor campaign implementation and assess performance.
- Improve coordination between the key implementing partners. HCT Nerve Centres must be urgently constituted within all districts, must have representative civil society participation and must be responsive to the challenges of the districts where they are located.
- Urgently expand the campaign to train, accredit and equip traditional healers to perform HCT.
- Put mechanisms in place to ensure the HCT policy is properly communicated to all health workers and that coercion for HIV testing and human rights violations are stopped.
- Ensure payment of lay counsellors with immediate effect to avoid further strike action and litigation as indicated below.

We as civil society commit to:

- *Participate in every local, district and provincial nerve centre within the regions our organisations operate in;*
- *Within each district to operate both as partners and as ‘watchdogs’ to hold implementers and managers accountable.*
- *Monitor consent and confidentiality in HCT and monitoring compliance with standards and guidelines.*
- *Coordinate civil society driven HIV testing drives;*

The HCT and Schools campaign

Extending the HCT campaign to school going children is important. But it is dangerous to do so without proper infrastructure and support systems being systematically put in place. To offer HCT is to acknowledge that children are engaging in sex, and yet government does not provide condoms at schools for children to practice safer sex. Furthermore, the schools campaign does not protect the rights of children. For example, there is already evidence that discrimination is endemic within our schools and communities. Addressing these concerns is essential.

We therefore call upon SANAC to convene an indaba on HIV testing among young people (including at schools) and to:

- Ensure government invests appropriately in the schools LifeSkills programmes;
- Dispense condoms within schools;
- Accelerate efforts to increase access to child-friendly health facilities.

We demand that school HCT campaign be suspended until the conclusion of the SANAC indaba. We further demand that the Departments of Health, Basic Education and Social Development ensure that schools in which HCT was conducted are:

- Monitored for adverse reactions;
- provide strong psychological and social support to children who tested HIV positive;
- Supported to address any stigma or discrimination that arises.

We also call on the Department of Basic Education to provide training for educators and to work with civil society to support parents so that they are empowered to discuss relationships, sexuality and reproductive health rights with their children that will complement more effective life skills in schools.

4. We demand the integration of Community Health Care Workers (CCWs) into the health system!

Implementation of both the NSP and the TB Strategic plan relies heavily on the work of almost 70,000 lay counsellors and community care workers. This cadre of health workers has shown tremendous dedication despite the fact that they spend months at a time without pay and are subject to labour broking and exploitation. Their dissatisfaction and unrest represents a major threat not only to the HCT campaign but to the HIV and TB response overall.

We call for CCWs to be paid immediately. We have made this call before but despite promises there has been little progress. We have resolved to initiate litigation should lay counsellors not be paid all outstanding monies by 30th October 2010.

In this regard we also note and support COSATU's Section 77 notice at NEDLAC to protest the use of labour brokers.

Through the SANAC Task Team on Community Care Workers, civil society has held extensive and productive consultations with the DOH on the CCW issue. But we express our frustration at the pace at which this critical cadre of health care workers are being integrated into the formal health workforce. Despite providing an essential service, CCWs operate without comprehensive training, supervision, norms and standards or pay. We call upon government to set a clear timetable to formally employ, train, manage and remunerate CCWs. We further call on government to commit to promulgating a *Sectoral Determination for Community Care Workers* which will provide directives on minimum wages, working hours, training, supervision and any further sector appropriate provisions.

Should government fail to provide a firm commitment or a satisfactory timeframe within three months (by 15th December 2010) civil society will be left with no choice but to litigate against the Ministers for Public Service and Administration, Labour, Finance and Health.

We as civil society will:

- *Continue to work with trade unions to help to organise Community Care Workers, document unfair and criminal labour practices, and monitor the implementation by government of proper labour conditions;*
- *Work with the Departments of Public Service and Administration, Labour, Finance and Health to seek a solution to this problem.*
- *Be prepared to litigate to enforce the rights of CCWs should no solution be found by 15th December 2010.*

5. We demand a Human Resources for Health plan by March 2011!

Despite a massive epidemic, an overburdened public health system and a population with devastatingly poor health outcomes the public health system continues to function with a vacancy rate (in 2008) of 90,000 unfilled posts. Human resource shortages of this magnitude will not be solved in the short term. They require a realistic but urgent long term plan to produce adequate numbers of trained health professionals.

High vacancies and low pay help to explain the anger that was witnessed during the 2010 public sector strike. We call on the Public Service Commission to investigate and report to Parliament on the conditions on public health workers.

We believe that it is unacceptable that the national *Human Resources for Health (HRH) Plan* is only scheduled for completion in 2012.

This crisis requires urgent action. We call upon government to:

- Identify and fill essential vacant posts;
- Expedite the finalisation and implementation HRH plan and to work in consultation with health care workers organisations in doing so;
- Distribute available human resources equitably between urban and rural areas;

- Incentivise doctors, nurses and pharmacists to remain in South Africa, to remain within the public sector, and to remain (or go into) in the areas of greatest need (often rural).

We also call upon government to spend human resource budget allocations and to plan and prepare long-term budget estimates.

We as civil society will:

- *Make every possible effort to work in collaboration with government to plan, project and cost the human resource needs in our country over the medium to long term.*

6. We demand expanded access to improved ART regimens, better HIV and TB drug regimens & TB Integration!

Great effort is being put into testing 15 million people through the HCT campaign. But we are concerned that many of the people who test HIV positive are not being properly referred for follow-up services: CD4 count testing, screening for TB and ARV treatment.

We call on government to:

- Urgently devise and implement basic monitoring and evaluation to end treatment interruptions;
- Link HIV counselling and testing to access to treatment;
- Implement a retention package and monitoring programme for HIV positive patient not yet requiring treatment;
- Strengthen TB HIV integration;
- Implement a single patient identifier system to track individual patients and monitor loss-to-follow-up.

Finally, we call upon the Mpumalanga Department of Health to withdraw the moratorium on initiating new patients onto treatment and to end treatment stock-outs in their province. We ask National Treasury and the National Department of Health to intervene to assume provincial functions in any province that is not able to carry out its duties to provide people with access to health care services.

We as civil society will:

- *Monitor and report drug stock outs*
- *Promote HIV testing, ARV & TB treatment adherence*
- *Carry out treatment and legal literacy campaigns within our communities*
- *Examine and improve on our own strategies of integration;*

7. We Demand a Plan for Sustainable National and International Financing of the HIV and TB Response!

The HIV and TB epidemic consumes a substantial portion of the health budget. Costing estimates anticipate that the South African response will require R41billion annually within the next five-ten

years. For the HIV response to remain sustainable we need to turn off the tap of new infections, derive cost efficiencies from within our existing programmes and have a sustainable funding plan. Health is a human right. We continue to call on government to invest “at least 15%” of the annual budget into the health sector as committed to at the Abuja Declaration in 2001 and as President Zuma reaffirmed at the African Union Summit in Kampala, Uganda in July 2010.

However, we support the principle that funding health is not just a national responsibility. The International Covenant on Economic, Social and Cultural Rights (ICESCR) makes it plain that there must be international co-operation on achieving the right to health.

The failure, in October 2010, to replenish the Global Fund on HIV, TB and Malaria (Global Fund) is a great setback for millions of people needing HIV, TB and malaria treatment. To this end we call upon government to lead an international campaign for a secure funding plan for the Global Fund. In particular we call on government to endorse an international Financial Transactions Tax (FTT) as among those measures that can make substantial funding available for global health.

We as civil society:

- *Commit to financial accountability, transparency, honesty and ensuring that our activities are effective and achieve the maximum impact for the level of our investment;*
- *Commit to working with the South African government and U.S. Governments in the negotiation of the PEPFAR Partnership Framework and advocating that PEPFAR funds be used in a way that both expands access to treatment and strengthens community and health systems.*
- *Will advocate that all bilateral and multilateral development partners commit to aligning their programmes with the objectives and outcomes expressed in the MTSF and NSP.*
- *Commit to improving collaboration with regional civil society to strength activism beyond our borders;*

8. We demand Social Assistance for people who are chronically ill!

South Africa has one of the world’s highest levels of income inequality and is suffering extreme levels of long term unemployment. South Africa’s HIV pandemic and growing chronic disease burden places enormous financial stress on households and the state. Tens of thousands of poor and vulnerable people living with a chronic illness do not receive social assistance. Many thousands of people who have chronic illnesses, notably those living with HIV and AIDS currently receiving a disability grant, are systematically falling off the social assistance system once their health improves, and we predict, once the new proposed definition of disability is legislated.

Addressing the health and economic burden of a chronic illness requires a shift from episodic care to a chronic care model characterized by continuity of care across the lifecourse, a proactive patient-focused and family/community oriented approach, active collaboration among individuals, communities, and shared risk factors such as poor nutrition and poverty.

Government has a positive obligation to ensure that everyone who is in need of social assistance receives it and therefore progressively realise the right to social security within its available resources. While in-kind support (vouchers, food parcels) and livelihood or micro-finance programmes are possible, cash transfers are by far the easiest social transfers to administer and take to scale rapidly. We have seen the success of conditional cash transfers in improving school retention in other African countries and, among girls and young women, the evidence even shows

marked reductions in HIV incidence. There is a very strong health case for an intervention like a conditional chronic illness grant that would increase household income and promote pro-social options and choices among youth and adults. It is an intervention to prevent relapse and protect an overburdened health system and the cost benefits should be seen in this light.

Civil society therefore calls on:

- The Social Cluster of government to reverse its decision not to implement a Chronic Illness Grant.
- SANAC to recommend that a chronic illness grant to be included in the social assistance system based on Section 27 (1) (c) of the Constitution;
- Government to extend its social assistance provisions to include all poor people who have a chronic illness;
- The Department of Social Development to immediately prevent poor people who are chronically ill and currently on the social assistance system from being moved off the system until a chronic illness grant is in place.

9. We demand that SANAC be revived as an effective and accountable institution driven by civil society priorities!

Civil society has invested heavily in trying to make SANAC work. This is because we recognise that it is critical for the national HIV response to be well managed and co-ordinated.

We welcome the appointment of a permanent staff to the Secretariat, including the CEO. But we are concerned that the restructured SANAC secretariat has done little to energise a comprehensive national response to the HIV epidemic. Many people from civil society see SANAC as bureaucratic, out of touch, top-down, and unaccountable.

We restate our conviction that SANAC requires an independent secretariat and a high level, outcomes oriented senior management team. But it cannot implement programmes.

We say this because this year the line between coordination and implementation was blurred. The SANAC secretariat has become embroiled in efforts to fill capacity gaps in a weak and underperforming National Department of Health. It is not SANAC's role to perform these functions. We call upon SANAC to focus on its existing mandate and on the National Department of Health to strengthen its weak management team.

These are some of our major concerns:

- After more than a year in office the new SANAC secretariat management team has yet to build a meaningful relationship with Provincial AIDS Councils. We call for the development of agreed terms of reference for PACs and DACs before the end of 2010.
- At the national level communication within SANAC is so poor that some national structures of SANAC say they have given up on all expectations of secretariat support.
- The secretariat does not employ a single person living openly with HIV.
- We express concern at the wastage of resources and frustration that SANAC was intended as a body that speeds processes up, not slow them down.

Civil society participates in SANAC structures because of SANAC's potential to bring together all role-players and to advise government at the highest level. A disconnected secretariat is not what was intended when we demanded the appointment of a Secretariat. Our participation in SANAC is conditional upon the ability of SANAC structures to be seen to be effective.

If these problems are not overcome by the end of 2010 we will reconsider our role in SANAC as we do not wish to be part of a structure that hinders the HIV and TB response.

We therefore believe it is necessary to:

- Rationalise the structures of SANAC across provincial and national levels;
- Improve interaction across all levels and to urgently update SANAC's procedural/operating guidelines.
- Reaffirm the independence of SANAC and to provide it with the institutional legitimacy and funding that will make this possible.

We request that the secretariat conduct an audit of the representativity and accountability of civil society sectors. It is not possible to coordinate nineteen independent civil society sectors and we are willing to rationalise our representation in order that we be more accountable and responsive to our constituencies.

We as civil society will:

- *Improve our own coordination, effectiveness and accountability by working within the CSMF;*
- *Continue to work hard in the structures of SANAC until such time as we no longer believe SANAC to be effective;*
- *Improve the communication of our collective efforts across each of our constituencies.*

10. Build independent, effective, accountable Civil Society organisations!

We have learned the importance of an independent voice and of the independent coordination of civil society. It is not enough to engage with government and participate in policy processes individually. Civil society needs to be better co-ordinated, more engaged with issues, better prepared to contribute evidence and ideas to improving the response to HIV/AIDS/TB and health generally and well organised to move with the necessary haste that our constituencies demand of us.

We have collectively agreed to improve collaboration and to regularly engage in the manner through which this consensus statement was developed. To this end we commit to establishing a Civil Society Co-ordinating and Monitoring Forum (CSMF). Amongst our plans are:

- A meeting to engage health worker unions in discussion about campaign to improve health worker conditions.
- To call on the chairperson and organisers of the 2011 Southern African AIDS conference to focus the conference exclusively on developing the 2012-2016 National Strategic Plan and committing to a collective HIV prevention roadmap/ strategy
- To meet again as civil society in January 2011 to assess progress with the resolutions in this statement.

Signed by:

The AIDS Consortium, Black Sash, Ceppwawu, Children's Rights Centre's, Community Media Trust (CMT), [COSATU], SA HIV Clinicians Society, HIVSA, HOSPERSA, MSF, NACOSA, [NEHAWU], Positive Life Project, RHRU, SECTION27, Soul City, the Treatment Action Campaign

[ENDS]