

JOINT CIVIL SOCIETY MONITORING FORUM

FOUNDED BY THE AIDS LAW PROJECT, HEALTH SYSTEMS TRUST, CENTRE FOR HEALTH POLICY, INSTITUTE FOR DEMOCRACY IN SA, OPEN DEMOCRACY ADVICE CENTRE, TREATMENT ACTION CAMPAIGN, UCT SCHOOL OF PUBLIC HEALTH & FAMILY MEDICINE, PUBLIC SERVICE ACCOUNTABILITY MONITOR & MÉDECINS SANS FRONTIÈRES

**Resolutions of the 7<sup>th</sup> meeting of the JCSMF**

***Assessment of the North West Province ARV rollout and the private sector's contribution to implementing HIV/AIDS treatment and care in SA***

Orkney, North West, 3 March 2006

**INTRODUCTION**

1. The JCSMF held its seventh meeting in Orkney, on 3 March 2006. The meeting was attended by over 25 organisations from the public, private, not for profit and civil society sectors. The meeting was held to assess the on-going progress of the *Operational Plan for Comprehensive HIV and AIDS Care, Treatment and Management* (Operational Plan) in the North West (NW) and to assess the contribution of the private sector towards providing HIV/AIDS treatment and care through medical scheme coverage and through workplace treatment programmes (WPTPs).
2. The meeting reiterated that membership to the Forum is open. It also stressed that the role of the Forum is to support the implementation of the Operational Plan by working with national and provincial health departments as well as with health care workers in all districts.
3. Apologies were received from Médecins Sans Frontières, Lifesense, Embassy of Ireland.
4. It was reported that the Minister, Director-General of Health, Head of the HIV/AIDS STD and TB Directorate and the Head of the National ARV programme were invited but did not respond to the invitation, nor acknowledged receipt of it. The Forum expressed its regret that national officials in the department of health have again failed to respond to invitations to attend the meetings of the JCSMF.
5. The Forum noted that the Operational Plan is in its third year of operation, but that to date there has been minimal qualitative assessment of the programme by the national department of health.
6. The Forum also noted that the National HIV/AIDS Strategic Plan (2000 – 2005) expired at the end of 2005. A new plan has not as yet been made publicly available.
7. The Forum received a report that the National Human Resources Plan (HRP) is due to be published in April 2006. The JCSMF will revert to the department on key issues once a draft final version is available. (see [www.doh.gov.za](http://www.doh.gov.za) for version released on 9 March 2006).

**TREATMENT ROLL OUT IN THE NORTH WEST**

8. The Forum welcomed the participation of the NW provincial health department (ARV programme). In summary, the presentation by Dr Sontle Maputle confirmed that about 12 500 patients are on ARV treatment (up from 130 in 2004). This exceeds the original provincial target of 10 000 by March 2006. Of these, about 2/3 of patients are women and 10% of the total number are children. Currently 9 sites are providing treatment – and 5 are to be accredited shortly.

9. With respect to increasing the scale and reach of the rollout the following challenges were identified by Dr Maputle:
- Insufficient staffing (HR) at treatment sites,
  - Problems with the sustainability of drug supply, particularly efavirenz (Merck Sharp Dome [MSD])
  - Over expenditure on laboratory tests and drugs (given that NW exceeded its targets).

In the discussion thereafter, health workers and other individuals working for NGOs in NW identified the following additional challenges:

- Expanding early access to PCR tests for infants born to positive mothers;
- Examining the labour implications of 'hiring' community based workers who work for free and/or on a stipend basis as well as addressing their legal status; and
- Addressing confusing treatment messages that are affecting service delivery and timeous access to treatment.

*The JCSMF therefore calls on government to issue unambiguous and scientific messages about treatment options for people living with HIV/AIDS; to provide a plan for filling key HR posts and to increase the use of PCR tests for early diagnosis of children after birth.*

## **THE CONTRIBUTION OF THE NON STATE AND PRIVATE SECTOR IN PROVIDING TREATMENT AND CARE**

At the outset, the forum was informed of and welcomed the new Revenue Amendment Laws that came into effect on 1 March 2006. The amendments provide that workers who benefit from off site workplace treatment programmes are no longer liable to pay fringe benefit tax.

(For further information visit: [www.sars.gov.za](http://www.sars.gov.za) and [www.alp.org.za](http://www.alp.org.za))

The forum heard the personal testimony of David, who is living with HIV and working for Anglo. David had recently commenced ARV treatment and urged employers and trade unions to ensure that WPTPs pay sufficient attention to stigma and confidentiality as well as ensure that they support programmes to encourage workers to get tested and get treated.

The forum noted that approximately 90 000 people receiving ARV treatment in SA are in the non-state sector – through medical schemes, workplace treatment programmes, donor sponsored not-for-profit programmes and the unfunded private sector.

The forum had the privilege of having several of the country's largest Disease Management Programmes (DMPs) present at the meeting: including Aid for AIDS, QUALSA, Aurum Health, Calibre Clinical Consultants; Right to Care and Discovery Health. Other DMPs were also invited but they were unable to attend. From the presentations certain common themes emerged:

- The overwhelming majority of employees who start ARV treatment recover wellness and return to work. Data collected by DMPs shows a dramatic drop in absenteeism.
- The two primary causes of non-adherence and drop out from programmes are death (due to late enrolment) and leaving employment.
- On all schemes the numbers of serious adverse events due to ARVs are very small. There is still a problem with late treatment, where the median CD4 at commencement is under 200. This affects treatment outcomes.
- There is still an under-enrolment of people on private sector programmes: it was believed that this is linked to fear of stigma; the lack of active promotion of HIV testing by medical schemes; enrolment on schemes by primary members – but not by their spouses and children (non-disclosure).
- While there is consensus amongst HIV clinicians in the private sector that d4t should be removed from the first line treatment regimen and replaced with tenofovir (has fewer side effects). However, tenofovir is not yet registered by the Medicines Control Council (MCC).

- The training and use of private GPs in the providing treatment is working, and if properly co-ordinated with government could provide an 'additional 5000 sites'.
- Lack of adherence is a key barrier to expanding access.

*The following challenges were identified by the above presentations:*

- There is a growing but largely untreated TB and HIV co-epidemic particularly in the mining industry.
- There is no clear policy from business on providing benefits to dependents of workers, and to foreign workers.
- There is no clear policy on continuing health related benefits for dismissed and retired workers.
- There are still high levels of stigma in and outside of the workplace. This is hampering disclosure and early access to treatment.
- In the private sector, the uptake of VCT is very low.
- Adherence requires even greater monitoring.
- Slow decision making provinces hamper the ability of the private and not for profit sector to respond effectively to the epidemic.
- Treatment literacy by trade unions and peer educators is necessary but often missing.
- Most DMPs use the SA HIV Clinicians Society (SAHCS) adult treatment guidelines. As such, the private sector is keen to work with government to ensure that protocol choices do not undermine the effectiveness of the Operational Plan.
- The delay in the registration of tenofovir is hampering decisions around optimal treatment regimens in the private sector.
- There is minimal interaction between the national department of health (ARV programme) and private sector providers, hence it is difficult to get accurate numbers of patients on treatment in the whole country. Often the private sector does not share information amongst itself.

*The JCSMF therefore resolved* to call on the national department of health to urgently attend to updating the national adult and pediatric treatment guidelines to include recent medical advances; the national department of health to exercise its duty in implementing the Operational Plan reasonably by bringing together all service providers, so that information in both the private and public sectors is collected, collated, shared and assessed.

*The JCSMF also resolved* to call on the private sector to ensure that strategies are in place to ensure that non-state programmes are sustainable; the private sector to develop policies that deal with provision of treatment for foreign workers as well as a strategy for the provision of benefits to dependants and finally a policy and industry norm to continue providing treatment for a period of at least 6 months after retrenchment.

It was agreed that key information and data gathered by all the private providers (on total numbers on treatment; on adherence; outcomes on CD4 & viral load; side-effects; etc) could be collated into a report that would provide an overview of the successes and challenges facing private sector provision in South Africa. SABCOHA announced that it would fund the development of this report.

## **THE REGULATORY ENVIRONMENT FOR MEDICAL SCHEMES**

The forum was privileged to hear Alex vd Heever from the Council for Medical Schemes (CMS) present on a number of emerging regulatory issues in the medical schemes environment. He reported on the following:

### **Risk Equalization Fund: Not implemented as yet**

- The shadow phase of implementing the REF has meant that the CMS has collected data from medical schemes about the number of people on ARV treatment (about 30

000) (handouts were given to participants)

- The REF has not yet been implemented. Its commencement (shortly) is expected to reverse the unequal spread of risk amongst schemes and thus prevent perverse incentives (e.g. marketing to attract young and healthy only).
- Through the REF- a central register of all persons receiving treatment (for chronic illnesses) will be administered by the CMS. This will be useful for collecting data of private sector trends in treatment and care.

### **Low income Medical Scheme (LIMS): Still in policy phase**

- The CMS and DoH is currently investigating the feasibility of implementing LIMS
- LIMS will be introduced for low-income workers who will have access to special and limited set of PMBs, that is, a smaller package of services – with ARVs though. LIMS identifies artificial barriers to access to increase access (to risk pool out-of-pocket expenses because of Medical Schemes Act framework)
- The rationale is to voluntarily encourage low income workers to contribute to a risk pool and benefit accordingly by saving on out of pocket expenses
- The draft discussion document has been submitted to government for consideration so at this stage several outstanding areas have yet to be addressed - funding mechanism of LIMS (which could involve a direct subsidy from government and a contribution from employers and employees, the latter contribution may be about R 200 per worker)
- As it stands, LIMS will require exemptions in terms of the Medical Schemes Act 1998.
- The process of finalising LIMS as a policy measure is now quite advanced. Interested parties are required to make submissions to the CMS fairly shortly. A draft LIMS discussion document will be released within the next week for public comment. A policy framework will be finalised by July 2006, with a legislative amendment to the Medical Schemes Act by early 2007.

### **NATIONAL ROLL OUT**

A short summary on the national rollout was presented by the ALP. According to data collected by it about 110 000 people are receiving treatment in the public sector, about 90 000 in the private sector. Most patients are hospital based, and women. Very few children are getting access, largely because they are not being diagnosed timeously. Access to information at a national level is also rare. (Further information is available from [www.alp.org.za](http://www.alp.org.za))

### **REPORT ON SOUTH AFRICA'S COUNTRY REPORT TO UNGASS**

Mark Heywood, a member of the SA National AIDS Council (SANAC) reported on the 'consultative' meeting convened by the Department of Health on 2 March 2006 to discuss SA's report to UNGASS on progress with the implementation of the UNGASS Declaration of Commitment (2001). He reported that the process of consultation had been wholly insufficient and that this had been raised by a wide range of stakeholders. A week had been allowed for comment on the draft report. After this, the SA report is to be submitted on 7 March 2006. Participants confirmed that none of them had been aware of, or consulted during, the process. It was agreed that a report should be prepared and submitted that reflected the real strengths and weaknesses of SA's HIV prevention and treatment efforts.

*The JCSMF resolved* to write to the UN and the SA presidency registering its opposition to the SA country report prepared by the national department. It undertook to reject the current version on several grounds including the lack of proper consultation with civil society, and the exclusion of substantial and important data and statistics (HIV related mortality, HIV prevalence, TB and HIV incidence, treatment targets etc) in the current version.

## Housekeeping

The next JCSMF meeting will be held in mid May or early June in Gauteng, Johannesburg. The following will be discussed at the next meeting:

1. Gauteng rollout
2. Access to laboratory services and new technologies
3. Presentation of UNGASS civil society report.

See [www.alp.org.za](http://www.alp.org.za) and [www.hst.org.za](http://www.hst.org.za) for previous resolutions and minutes of JCSMF meetings.

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