

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 6th meeting of the JCSMF

East London, Eastern Cape

14 November 2005*

***4 November 2005 marks the second anniversary of the adoption of the Operational Plan**

The JCSMF held its sixth meeting in East London on 14 November 2005. The meeting was attended by at least 20 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) and to monitor resource allocation and utilisation for HIV/AIDS interventions. In particular, the forum assessed the contribution of donor programmes towards implementation of the Operational Plan. The meeting also marked the commemoration of the second anniversary of the adoption of the Operational Plan. A copy of the minutes and presentations made at the meeting will be sent out separately.

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.

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 failed to respond to the invitation. Again, the forum calls on government to seriously engage with civil society instead of ignoring it. The Forum emphasised its commitment to supporting the implementation of the Operational Plan. As stated in previous forum resolutions, for civil society to work in collaboration with government, accurate and updated information about the state of implementation of the Operational Plan in each province is vital. Where this is absent, it

makes it very difficult for civil society to assist. The meeting therefore concluded that the NDoH and government must work more closely with civil society. Again, the Forum repeated that its aim is to make the Operational Plan work, not to revel in its limitations

The Eastern Cape provincial health department and the Director and Deputy Director of the HIV/AIDS STD Prevention Unit attended the meeting - Mrs Makwedini and Mrs Nqini. The Forum welcomed their participation and was particularly grateful for their input throughout the entire meeting.

The forum received a report from the ALP indicating that Dr Kalombo of the NDoH had stated at a meeting in Johannesburg that 86 000 people were on treatment in the public sector at the end of September 2005. Unfortunately, official provincial, age and gender breakdowns are not available. Forum members were not in a position to confirm the figure of 86 000. The Forum recognised that this is a step forward, but felt that the number does not meet the actual demand for treatment. The Forum expressed disappointment that two years after the Operational Plan was adopted, so few patients (and in particular children) are on treatment. This is not because of a lack of demand for treatment. Many participants mentioned long waiting lists at places such as Stanger Hospital in KZN as well as at most treatment facilities in the Eastern Cape, especially Umtata General Hospital – at the latter this is mainly because of a shortage of pharmacists in the province.

The forum noted that the NDoH has yet to issue updated guidelines on counselling and testing, PMTCT interventions and ARV use, without which, it is difficult to ensure that the public, not for profit and private sectors are complying with the same norms and standards.

The forum also heard that the NDoH has not yet finalised the national Human Resources Plan. The forum again calls on government to finalise the HR Plan and address salaries and living conditions of health care workers. Participants also felt that specialist nurses are needed to alleviate the burden of nurses and that more adherence counsellors should be appointed to assist nurses.

The Forum also heard reports that soon laboratory tests conducted by the NHLS will require an identity number from a patient. The Forum expressed concerns about access to laboratory services for patients without an ID and also whether such information will be kept confidential. It undertook to raise this issue with both the NDoH and NHLS.

The forum heard the personal testimony of Portia Ngcaba - a woman living with HIV who has been on ARV treatment since 2002. Portia spoke about her experiences of starting and continuing with ARVs as well as about losing a child to AIDS and subsequently having a child, who as a result of the PMTCT programme, is HIV negative. She raised several important issues around the availability of drugs to treat and prevent opportunistic infections, long waiting lists and issues of reproductive and sexual health. She pleaded with the forum to ensure that opportunistic infections are treated properly and timely. She also pleaded for the general availability of the HIV DNA PCR test – which determines a child's HIV status 6 weeks after birth.

PRESENTATIONS:

1. DELIVERY OF HEALTH SERVICES IN EC

The PSAM provided an overview of general challenges for improving health delivery in the Eastern Cape. It reported on a number of issues and made several recommendations for improving health services.

It reported that:

- During the 2004/05 financial year the Eastern Cape Health Department under spent its overall health budget by R50.83 million.
- That the Department recorded under spending across all eight programmes and that the HIV/AIDS sub programme failed to spend 12.73% or R16.80 million of its overall budget.

The PSAM identified the following areas of concern for the Department's 2004/05 financial year performance:

- Severe staff shortages. The Department had an overall vacancy rate of 32.8% during the 2004/05 financial year.
- Emergency Medical Services (EMS): There was a budget cut from R211.30m in 03/04 to R126.89 m 04/05. The programme had a 49% vacancy rate during the 2004/05 financial year.
- Poor spending on infrastructure and equipment.
- Over-expenditure burden: poor planning and management of budgeted funds has negatively impacted service delivery.
- Audit Disclaimer– the Auditor-General reported poor financial management and internal controls.

The PSAM also reported on the Department's Conditional Grant Spending. The Department failed to spend R94.62 million or 14.89% of its total conditional grants allocation. The PSAM identified the following areas of concern for the Department's performance on conditional grant spending:

- Over a 4-year period the Department has failed to spend R172 m dedicated for HIV/AIDS treatment, training, development of health care professionals and the provision of nutrition.
- There was poor spending on training and infrastructure.
- Though HIV/AIDS spending has improved it is still too slow. For example: the department under spent its 2004/05 HIV/AIDS Conditional Grant by 8.5% or R8.43 million.

The PSAM made the following recommendations:

The department must:

- Attend to the critical staff shortages by improving working conditions and addressing low morale.
- Improve its planning, budgeting and financial control.
- Ensure that all funds dedicated to HIV/AIDS are spent accordingly.

The Forum resolved to closely monitor the effectiveness of the department's programmes (staff recruitment, infrastructure development, service quality improvements etc.)

The Eastern Cape Head of HIV/AIDS STI Mrs Makwedini responded to aspects of the presentation that were within her unit's knowledge.

Mrs Makwedini reported that:

- There are 26 accredited ARV sites in the EC. 20 are operational and providing ARVs and at end September 2005 they were treating about 9664 patients (includes about 838 children), Cradock hospital for example has been unable to start due to HR shortages. Regarding side effects, thus far, 5 cases of lactic acidosis have been reported. The patient target for March 2006 is 15 000 patients – though it is likely that more than 15 000 patients will be put on treatment in 2006.
- Patient caps are not being imposed at any of the sites and therefore patients should not be turned away on the basis that the facility has reached its capacity,
- PCR testing should be generally available in the EC, and
- The EC provincial health department will soon have its own website with information about the ARV programme. This is in response to difficulties the HIV unit has had in the past in dealing with voluminous requests for information,

- The EC provincial health department has been working with the TAC in providing joint
- Training for health care workers, and
- Mrs Makwedini acknowledged the usefulness of the PSAM's presentation on the "Evaluation of Departmental strategic plans" at the Eastern Cape Treasury Medium Term Expenditure Committee (MTEC) hearings. Mrs Makwedini undertook to incorporate some of the PSAM recommendations (for example population density in relation to ARV rollout) in the Directorate's needs analysis

In terms of challenges, Mrs Makwedini listed the following:

- Fluconazole is not generally available at clinic level,
- The scope of practice for nurses has to be revisited with the SANC (blood taking),
- Patients need more treatment literacy and civil society has to assist with literacy efforts,
- Staff require more training on administering ARVs,
- Provincial staff needs training on how to comply with the requirements of PFMA and DORA (financial management skills).

The Forum acknowledged the role that Mrs Makwedini and her Deputy, Ms Nqini have played in showing immense dedication and stewardship in expanding the ARV programme in the EC. Officials like them have shown that with the requisite will, oversight and leadership, the programme can succeed.

2. DONORS AND THEIR CONTRIBUTIONS TO SUPPORTING THE OPERATIONAL PLAN

Several donors presented on the work they are doing in terms of supporting the implementation of the Operational Plan. The forum recognised that were it not for the work of these donors then government would not have been able to manage to fund and support the +/- 86 000 patients who are on treatment. The forum congratulated and saluted these donors for the important contribution that they are making to improving health in the public and not for profit sectors in South Africa.

The Futures Group and DFID

The Futures Groups serves as DFID's management and administrative consultancy in HIV and AIDS related activities in South Africa. The DFID HIV & AIDS Multisectoral Support Programme (MSP) was designed by DFID in consultation with key South African partners

during 2001/02. It distributes its funding of £ 30 million through six public sector and seven civil society organisation (CSO) beneficiaries or partners. These include National Government (£ 11.6 million) through the departments of health, social development, defence; Provincial Governments (£ 6.7 million) through Eastern Cape, KwaZulu-Natal and Limpopo. £ 9.5 million is distributed to and utilised by civil society organisations, namely: the Nelson Mandela Foundation, Anglican Church of Southern Africa/Christian Aid, HSRC/SAHARA. African-Asian Society/ Joint Economic AIDS and Poverty Programme (JEAPP), Society For Family Health and SABCOHA. DFID provides a £ 0.5 million to UNAIDS to contribute in its work in South Africa. Challenges common to public sector partners identified include absorptive capacity, under-expenditure and fragmentation of programmes.

Absolute Return for Children (ARK)

ARK is a UK-based children's charity organisation that seeks to help minimise orphan hood and vulnerability of South African children and their carers affected by HIV. It seeks to improve on access, sustainability and adherence to prevent fragmenting the continuum of care. ARK is operating from KwaZulu-Natal and Western Cape and is in the process of covering Mpumalanga and Eastern Cape. It rolls out ARVs at a primary health care level where the majority of patients access health services. Challenges faced in the expansion of ARK programmes in SA include the finalisation of Memorandums of Understanding (MoU). ARK is supporting just about 4500 parents / carers and as a result about 7000 children are indirectly benefiting.

Médecins Sans Frontières (MSF) – Lusikisiki

MSF provides a comprehensive HAART package for people living with AIDS. Its success stories come from its strategic structural and operational arrangements, which are primary, health care and clinic-based, nurse-managed, community-driven and patient-centered. MSF provides services such as patient preparedness through treatment literacy and community mobilisation driven by the Treatment Action Campaign (TAC); one-on-one support provided by treatment assistants as well as counselling support provided during clinic visits; peer support through specific HAART support groups, and; provision of adherence materials such as the Pill Box (with customized packing instructions), daily self-monitoring form and a simplified regimen. Nationally, MSF is indirectly supporting about 4300 patients in SA (In Khayelitsha about 3100 patients including 260 children and in Lusikisiki 1200 patients including about 90 children).

European Commission

The EC has contributed funding the Public Health Sector Support Programme (€43 million) which ended in December 2004; Partnerships for the Delivery of Primary Health Care including HIV and AIDS (€50 million); Support to the South African Comprehensive Plan for HIV & AIDS Care, Management and Treatment (“SuCoP”) (€25 million); Higher Education AIDS Programme (“HEAIDS”) (€20 million), and; Regional HIV & AIDS Awareness Programme (“Soul City Regional”) (Joint Programme (€33 million). It does not directly fund patients on treatment.

PEPFAR

CDC, USAID and the US Embassy implement the programme jointly – with a major focus on supporting the government and the public sector program – 75% of patients supported by PEPFAR (40,181) are in the public sector. Its main goal is to increase access to ART by providing support in the public, private and NGO sectors. It reported that two conditions are attached to being eligible for PEPFAR money, (a) use of US FDA approved drugs and (b) signed declaration that the recipient organisation will not promote sex work. PEPFAR reported good outcomes in the last 18 months of implementation by supporting treatment in more than 130 sites in the public, private and NGO sectors – this includes sites in the SANDF. There are 20 organisations funded to provide direct treatment support. Of the 40,181 patients funded through PEPFAR, approximately 9% are children – a ratio that the US Government would want to increase in 2006.

Donor concerns

The forum heard that even though donors are supporting public health facilities as well as other government departments with technical and other support – they nevertheless continue to experience long delays in getting MOUs signed. Some reported distrust by provincial officials and warned about ensuring the sustainability of donor programmes. Donors reported that in the absence of a national Management Information System (MIS) it is difficult to collect accurate and proper data on key indicators for the overall effectiveness of the ARV programme. Donors have individually collected data regarding their own programmes, which indicate excellent outcomes for patients on treatment (including children). Their support therefore has a direct impact on people’s lives and their ability to be productive members of our society.

Donors also indicated that at times there are poor response levels from government, which is best, described by “We will call you!” Further, the public sector seems to be very

suspicious of the help being offered by donors and often demands control mechanisms that are slow and inevitably fruitless.

Other issues raised by donors that require the assistance and intervention of the Forum and the NDoH:

- Resolve provincial and municipal conflict / tension that is affecting the delivery of child health services especially in the Western Cape;
- Home Affairs, the NDoH and the HPCSA have to fast-track foreign HCW registration especially in provinces where attempts are being made to redress the HR crisis in the short term;
- Civil society has to ensure that the ARV programme eventually becomes nurse driven and not hospital based;
- Increase the number of children on treatment and call on drug companies to make easier and simpler drug regimens for children.
- Address confusion and lack of political leadership in some parts of the country where patients are being encouraged to stop taking ARVs and instead take vitamin supplements; and
- The fluconazole donation has to be monitored more closely.

Therefore:

1. The Forum repeats its call on the NDoH to take urgent steps to ensure that all treatment sites treat children. In this respect, the Forum notes that the concerned paediatricians group (CPG) met on the same day as the 6th Forum meeting. The forum will continue to work with the CPG
2. The Forum calls on Pfizer to improve delivery of fluconazole to the not for profit sector and primary clinics
3. The Forum calls on PEPFAR to use ARVs that are duly registered for use by the MCC (like the SA government) so that more patients can be treated using affordable generics. The requirement of exclusively using FDA approved drugs was unnecessary because the MCC has sufficient controls in place to register safe and effective medicines
4. The Forum calls on government to finalise the issuing of key guidelines as well as adopting a proper Management Information System (MIS)
5. The Forum calls on the EC health department to:

- Attend to the critical staff shortages by improving working conditions and addressing low morale.
- Improve its planning, budgeting and financial control.
- Ensure that all funds dedicated to HIV/AIDS are spent accordingly.

The next meeting of the JCSMF will be held end February 2006 in North West, Klerksdorp - contact Penny Penhall penny.penhall@sahivsoc.org for more information.

***For more information about the outcomes of the 6th JCSMF please contact:
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