

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 3rd meeting of the JCSMF

Durban

18 February 2005

The JCSMF held its third meeting in Durban on 18 February 2005. The meeting was attended by over 18 organisations from the public, private and civil society sectors. The meeting was held to assess the progress of the *Operational Plan for Comprehensive HIV and AIDS Care, Treatment and Management* (Operational Plan).

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.

The meeting had a special focus on access to care and treatment for children living with HIV/AIDS.

Again, members lamented that the national political seriousness that is required to drive the programme is missing. However, the efforts of provinces such as the Western Cape, Gauteng, Free State, Northern Cape, North West are recognised and supported. Many health care workers around the country are working tirelessly but they need effective management, coordination and visible and unambiguous political commitment in order for the programme to provide optimal results. The meeting expressed concern about what appears to be efforts to stigmatise and discourage treatment by the placing of public advertisements containing wrong and misleading information about ARV treatment in major newspapers. The forum calls on government to intervene and state categorically its faith in medicines which are registered by the Medicines Control Council, and which form a key component of the Operational Plan. This will confirm that they are adopting a more serious and urgent approach to prevention, treatment and support.

The meeting heard painful personal testimonies of a mother living with HIV and her struggle to get access to treatment for both herself and her son. It also heard the testimony of a grandmother whose daughter and grandchild died because they could not access treatment in time.

The meeting received reports from KZN Department of Health, Free State Department of Health, Anglo American, Health Systems Trust, IDASA, AIDS Law Project, MSF, TAC KZN, Children's Rights Centre and the KZN Civil Society Monitoring Group. It is grateful for the active participation of paediatricians from KZN and Free State.

The meeting commended the KZN and FS provincial departments for attending the meeting. Also, forum members specifically acknowledged the release of national patient numbers and site details by the office of the national manager of the ARV programme. This is the first time that such information has been released publicly.

Attached are figures compiled by the Health Department that summarise the position in each province.

Notes on the national statistics:

These statistics were compiled by the national department of health on the basis of information supplied to it by provinces. According to the statistics, more than 113 sites are providing ARV treatment.

The figure for KwaZulu-Natal at the end of January 2005 is 8467, with at least 500 children on treatment. The low figure reported for December 2004 in KZN was probably due to inadequate data collection systems resulting in under-reporting.

In Mpumalanga end January 2005 figures are close to 1000 patients with about 31 children (under 14 years).

Summary of national statistics

About 27 000 people were on treatment at public facilities as at the end of December 2004. As at end January 2005, about 29 000 people were on treatment. These figures include donor funded (whole or part) patients that are receiving treatment at public facilities through public-donor partnerships. Such donors include MSF, ARK, SACC, Crusaid, RHRU, PHRU, etc.

Patient numbers for donors that are providing treatment outside of the public sector – such as Ndlovu HAART, ACTS, TAC TP, SACBC are not included in the national public sector figures:

The meeting expressed concern about the small number of children who are accessing ARV treatment at public facilities – less than 3000. Already, some provinces such as KZN have indicated that its paediatric targets for 2005 will not be met. The meeting resolved to investigate the factors that are preventing provinces from speedily expanding paediatric treatment.

It was accepted that generally, for both adults and children¹, the demand for treatment continues to outstrip supply. Patients are coming forward and seeking treatment, but at many sites, they are being turned away.

The main barriers to accessing treatment were identified as:

- (a) Severe shortage of human resources, especially doctors, nurses, pharmacists and counsellors.
- (b) Lack of information amongst people living with HIV and AIDS about treatment options. In particular, caregivers are unaware of treatment options for children.
- (c) Unsustainable supply of drugs occasioned by an as yet incomplete procurement process.
- (d) Lack of access to laboratory services for CD4 and viral load testing.

The meeting noted that very large numbers of children need access to treatment. Even though outcomes of ARV treatment for children are good, it is still dependent on:

- (a) The timely initiation of treatment.
- (b) The implementation of proper and holistic subsidiary care programmes for children living with HIV but are who are not on treatment, or are living with HIV and are waiting to start treatment.

It was reported that several factors are preventing greater paediatric access, including:

¹ The meeting acknowledged that the legal (0-16/18) and medical (0-14) definition of children does not adequately address the needs of all children and that this disjuncture has the potential of overlooking the needs of older children as well as that of very young infants.

- (a) The length of time it took for the national department of health to finalise treatment guidelines for use by provinces, resulting in some provinces developing their own guidelines before the finalisation of the national guidelines.
- (b) The “fear” of treating children (by doctors and nurses). Given that adult treatment is the main focus, the inadequate and insufficient training on paediatric treatment contributes to HCW reluctance and fear.
- (c) The misconception that only a paediatrician can treat children with ARV medicines.
- (d) The shortage of doctors and nurses in rural and/or remote areas.

To address these challenges the meeting recommended that:

- (a) Improved political commitment is required to increase health services for children and adults.
- (b) Sharing of information is vital at a national, provincial and district level.
- (c) Paediatric targets and improved monitoring and evaluation are urgently required.
- (d) PCR tests (to detect HIV in infants and young children) must be available at all treatment and referral sites. HIV PCR testing should be included as part of IMCI (Integrated Management of Childhood Illnesses) and linked to immunisation coverage. This way, children will not be lost to follow up and can be identified easily.
- (e) The urgent distribution of the national paediatric guidelines to all provinces and the amalgamation of provincial guidelines (KZN, FS) with the national protocol is required.
- (f) Education and advocacy concerning the treatment of children with HIV/AIDS within the medical profession must be improved so that children can benefit from the implementation of the Operational Plan on a much wider scale.
- (g) More effort is needed to strengthen the MTCT programme, particularly in Provinces such as Mpumalanga where the programme seems not to have been implemented at all.

General comments

Forum members regretted the apparent and ongoing lack of commitment to the national ARV rollout by the national Minister of Health and the President. In particular, the President failed to discuss the Operational Plan in his state of nation address delivered on

11 February, nor did he account for the imminent failure to treat 53 000 people by March 2005, as promised by him last year.

The meeting noted with concern that the Minister of Health refused to answer questions relating to patient targets and the implementation of the Operational Plan at a Parliamentary media briefing held on the same day as the Forum meeting.

Forum members noted that eight provinces have made public their business, strategic, treatment and HR plans (where available). Unfortunately, KZN is the only province that has refused to do so. The forum calls on the KZN provincial government to release the information in the interests of public accountability and transparency.

The meeting also discussed the continued challenges of the lack of adequate human resources (HR):

- (a) It was reported that there is still no national HR plan for the health sector. This is worrying because community doctors mainly staff many remote areas. This results in a high turnover of staff at individual sites. As a result, interruptions in services and programmes also occur. It was noted that often the scarce skills allowance and rural allowances are insufficient mechanisms to resolve the crisis of staff shortages in remote areas. In other words, working and living conditions must also be addressed in conjunction with the evaluation of scarce skills and rural allowances. The Minister of Health's claims that wage allowances have been successful in recruiting HCWs must be further investigated as it appears unfounded.
- (b) The meeting also recognised that partnerships with the private sector and donor agencies are vital in ensuring that the health sector copes better with the demand on its services.
- (c) It was agreed that systems are required for the 'down referral' of patients using ARVs who are considered stable, in order to free up tertiary centres for new patients and those needing closer on-going management and care.
- (d) The meeting recommended that sites must urgently invest in administrative systems for data collection so that effective monitoring and evaluation (M & E) can be carried out. This will prevent over and under reporting and allow for the successful monitoring of adherence. Anglo

American corroborated the intensive effort required to put systems in place to properly manage and support the rollout of treatment as well as the benefits that accrue once those systems are in place.

- (e) While government has set in place national M & E indicators, it is unclear if data is being collected according to these indicators. Also, if it is, it is not being made available – therefore it is difficult to assess the clinical impact of the Operational Plan and that of the MTCT programme.

The meeting also noted with concern the severe and disproportionate impact of HIV/AIDS on young women and girls, highlighting the urgent need to intensify our efforts to protect women and girls from sexual coercion, abuse and violence.

The meeting expressed its disappointment that the national drug procurement process has not yet been concluded. In view of the growing demand for treatment the incomplete process is likely to cause further delays in treatment access at a provincial level and is likely to force provinces to spend more money because they have to rely on procuring medicines on a monthly basis. Already, this is happening in the Western Cape, where it was reported that the provincial government has been forced to pay substantially higher prices for generic medicines from Aspen Pharmacare compared to the price that they paid a few months ago for the same medicines from the same company. The Forum agreed that it will request Aspen Pharmacare to explain the sudden price escalation for medicines that are being used in the public sector.

On budgetary aspects of the Operational Plan, it was reported that due to lack of disaggregation in HIV/AIDS expenditure reporting, it is difficult to monitor how the 2004/05 ARV budget was spent on antiretroviral medicines. There still remains a need to prioritise other areas of HIV/ AIDS spending - prevention and care and support.

The Forum agreed that additional allocations for HIV/AIDS for the 2005/06 financial year is needed. The capacity for expenditure at provincial level must also be addressed. In particular, national government must find a way to assess the extent to which provinces are underreporting total health HIV/AIDS spending as opposed to actually spending and reporting on conditional grants, given the fact that some provinces such as KwaZulu-Natal and Gauteng are spending large amounts from their own budgets in addition to national government's conditional grants.

The meeting concluded that:

- There is a need to fast track protocols and accreditation of sites for the purposes of treatment, especially paediatric treatment. Clarity must be provided at a national and provincial level about the criteria for nurse-driven paediatric programmes- that is, ensuring that tools are developed so that nurses are trained on how to assess, diagnose and treat children living with HIV/AIDS. In this respect, the meeting endorsed the resolutions and recommendations of the preliminary national consultation on paediatric HIV/AIDS treatment advocacy held on 31 January 2005 in Durban. A copy of the resolutions is available from the Forum secretariat.
- There is a need to devolve treatment to clinic level, to overcome treatment bottlenecks in hospitals and academic sites. Paediatric treatment must be strengthened at primary care level.
- There is a need for greater commitment from provinces (especially KwaZulu-Natal) to publicly disseminate and disclose all relevant information about the progress and limitations of the programme, including provincial business and treatment plans, treatment sites, patient and site targets. The Free State provincial health department use of a web portal, which regularly updates the public about its programme, illustrates that information dissemination does not hamper service delivery.
- The drug procurement process must be finalised with a view to securing competitive prices and a sustainable supply of medicines.

The Forum restated its commitment to supporting the implementation of the Operational Plan. For civil society to work in collaboration with government, accurate and updated information about site details, patient numbers, gender and age distribution and adherence is vital. The meeting concluded that government must work with civil society.

The Forum's aim is to make the Operational Plan work, not to revel in its limitations.

The 4th Forum meeting will take place in April 2005. Issues for discussion will be public messaging & education, an update on new drugs and the latest science on HIV/AIDS; the extent to which the Operational Plan has led to new staff joining the health sector and a detailed analysis of 2005-6 budget (national and provincial)

Ends

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