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

Report on the 5th JCSMF meeting held on the 29 August 2005

Khayelitsha, Western Cape

Introduction

The 5th meeting of the forum focused on reviewing the progress in each province and nationally in the provision of HIV treatment, and sought to reflect on progress in the light of the need for Antiretroviral therapy (ART) in each province. The Forum members had noted the encouraging increase in access to ART over the previous year, but felt that there were large inter-provincial discrepancies, and that it would be of value to take stock of progress on a province-by-province basis during the 5th meeting. The meeting was attended by over 20 organisations. The holding of the meeting in the HIV clinic at Site B, Khayelitsha, was symbolic as this was one of the first clinics to provide ART as part of a free routine service in the public sector. The meeting began with Dr Goemaere explaining how the service had evolved over time, through to the recent move to a new building where care for tuberculosis and HIV are delivered as a single integrated service.

Formal apologies were received from the office of the National Minister of Health, the Deputy National Minister of Health and the Western Cape Minister of Health. In the light however of requests from the national department of health (NDoH) to be able to attend the JCSMF meetings in order to respond to some of the issues raised in previous meetings, forum members noted the failure of a single official from the NDoH to attend the meeting in spite of numerous invitations and prior telephonic confirmation. The Forum reiterated its wish to work with government in making the programme a success.

Provincial ART access relative to need

The meeting began with an input from Leigh Johnson of the Centre for Actuarial Research (CARE) at the University of Cape Town (UCT). Provision of treatment was presented relative to the numbers of newly AIDS symptomatic individuals in each province and nationally based on the ASSA2003 model. The results are provisional and are not yet available for public dissemination. A number of important points did however emerge:

- Provision in some provinces is approaching or has exceeded 50% of those projected to be newly AIDS symptomatic. Although this assessment does not include the backlog of patients who were already symptomatic, it does demonstrate that progress can be rapid if supported by both resources and commitment.
- Huge inter-provincial variations were apparent, with the worst-performing provinces covering less than 10% of those newly in need of care (Free State, Mpumalanga and Limpopo). This highlighted the urgent need for national support and leadership in certain provinces.
- Nationally less than 1 in 5 patients diagnosed with AIDS in the public sector are able to access ART at present assuming all new patients starting ART are newly diagnosed with AIDS. We know however that many of those who have started ART in the past year have been waiting for a long time for treatment, so probably even less than this proportion of newly AIDS-symptomatic patents are currently accessing ART in the public sector.
- Modelling ambitious increases in current coverage (i.e. keeping up with new demand at existing coverage levels plus increasing coverage by a further 10% absolute per year) would still result in far fewer South Africans being on ART than originally anticipated in the comprehensive plan. However 200,000 patients at the end of 2006 is achievable under this scenario
- Although the total numbers of patients on treatment in the public and private sector are currently almost equivalent, the coverage of those in need in the private sector is much higher and will most likely increase even further now that ARV's are a prescribed minimum benefit.

Discussion on Western Cape roll-out

Dr Neviline Slingers, programme manager for the Western Cape ARV programme, spoke briefly about some of the challenges faced in the Province, and responded to a report prepared by some of the NGO's and academic partners in the province. Dr Slingers identified physical infrastructure and

recruitment of staff as being the major bottlenecks, as well as the lack of middle-management to oversee the programme. The civil society report for the Western Cape (UCT School of Public Health and Family Medicine) raised the following issues:

- There has been a rapid increase in enrolment, and many clinics are reaching what they think could be capacity. In high burden areas the vision for the future expansion of the HIV care platform is not necessarily shared, and partners sometimes feel alienated
- The lack of middle management was also identified as a major obstacle to effective service management
- Waiting lists are variable – many sites contacted could enrol a patient within days or weeks if required. There are however some areas where patients wait three months for an appointment, and others where services are still disproportionately hospital-based, especially in the case of children
- Currently one in four adults starting ART in the Western Cape have CD4 counts below 50 cells/µl. There is a sense though that the services are not reaching out to the asymptomatic eligible population, and some sites still report high mortality in patients being prepared for ART
- PMTCT generally is accessible, although the model of referral of pregnant women with low CD4 counts to ARV sites (sometimes distant) was still identified by a number of clinicians as a problem with the danger of loosing the women most at risk of vertical transmission.
- There do not seem to have been major problems with drug supply or laboratory services
- Referral networks varied, and are highly dependent on local relationships. Where successful, relationships with referral institutions were identified as a key enabling feature

A long discussion followed about the lack of adequate provision of paediatric care in clinics, and linked to this the obstacles inherent in the division of primary care services in the metropolitan area between local and provincial government. Clinicians present at the meeting expressed extreme frustration at the impact this was having on the rational provision of care, such as the inability to transfer more paediatric ARV care to primary care sites.

A report on the treatment numbers by district in the province was available to the meeting. Although outcome reports based on the cohort monitoring system had been presented to programme staff, these are not yet publicly available.

Discussion on other provinces

Free State (UCT Lung Institute)

Representatives of the Lung Institute at the UCT were present at the meeting. They are integrally involved in the Free State programme, and were able to

provide detailed information on developments. They identified the threat of drug shortages as having impacted on the speed of enrolment at one point, and fielded criticism that the programme had moved too slowly relative to the capacity and resources available to it. A report on the enrolment and outcomes in patients by the middle of 2005 was available to the meeting. Bloemfontein was identified as a major area where accessibility of services is far behind the need for ART. The conditional grant for HIV/AIDS had apparently still not been approved, and this was a cause for concern. As the Free State programme is largely nurse driven, and the meeting heard how nurses had responded with enthusiasm and willingness to the challenge of providing ART, a discussion ensued on the professional development of nurse clinicians. The idea was proposed that nurse clinicians who work in ARV programmes would benefit from a specific clinical career path such as Clinical Nurse Practitioner certification. The fear of taking blood in children was identified as an impediment to paediatric ART provision in primary care, and questions were raised about technological developments that would simplify the follow-up of children on ART. Human resource challenges are reportedly greatest in the rural areas of this province.

Gauteng (Centre for Health Policy)

Data are available on patient numbers, but had not been provided by the time of the meeting, although anecdotally around 20,000 patients are on ART in the province. There is a feeling that the demand at the academic hospitals may be decreasing, possibly as a result of user fees and transport costs. There are currently attempts to remove the user fees for ARV patients. Support for sites is generally good, although many of the networks are informal, and attempts are being made to formalize these.

Eastern Cape (Public Service Accountability Monitor)

A detailed report was presented by PSAM on developments in the Eastern Cape. Civil society has generally struggled to get up-to-date information from the DoH in the province, but were able to provide an indication on the rate of enrolment based on reports in the media. Many sites had reported problems with drug supply and shortages, and there are ongoing issues around the management of drug depots in the province. It was felt that in this province there is a severe lack of management capacity at provincial level in spite of some officials being very committed to the programme.

A discussion on monitoring followed on from the observation that in some provinces there is a general reluctance to share information with civil society, whilst in some other Provinces this reluctance does not exists but there is a genuine difficulty in assembling the information and a fear of disseminating incorrect information. The lack of simple tools and technical support for monitoring at site level was identified, and a number of people spoke of the confusing lists of indicators that are repeatedly circulated for collection by provinces and sites.

Mpumalanga (AIDS Law Project)

A recent visit to Mpumalanga by ALP struggled to get information on developments in the province concerning the provision of ART. Health workers that had been spoken to queried the accuracy of official data provided by the DoH, and NGO and government health workers differed in their assessment of the demand for care. Some of the rural sites reported concern about laboratory service availability. There are a number of private and NGO providers in the province, possibly providing a large proportion of all ART care in the province (estimated at 45%). There were many concerns expressed about the quality and availability of PMTCT in the province.

Northern Cape

There was no-one at the meeting in a position to report on developments in the Northern Cape. The Provincial DoH were however able to share information on the programme enrolment on request. The TAC had received reports of difficulties for some patients in accessing hospital based sites due to the distances involved.

North West Province

None of the forum members at the meeting were in a position to report on the NW province. Members had received encouraging reports on the commitment to and rapid increase in HIV service availability in the province. Some forum members questioned whether there were enough formal linkages between Gauteng and Limpopo, North West and Mpumalanga given the human resources available in Gauteng. There was also concern that patients living very close to each other but on different sides of the provincial border with Gauteng could end up with vastly discrepant access to ARV care.

Limpopo

The meeting was greatly concerned about the lack of information on Limpopo. Health workers in the province reported that they could not speak about HIV services under threat of disciplinary action if they do. There are apparently only 8 accredited sites in the province, and unlike other provinces, there are fewer NGO health service providers filling the gap. The delay in accreditation of Tintswalo hospital was raised as a particular problem given the enthusiasm for over a year of clinicians to provide ART.

KZN

There was no-one at the meeting in a position to report on provincial developments in KZN, although the TAC had worked with one of the districts in the province where there was a large backlog in treatment provision in spite of a rapid increase in enrolment this year. ARK as an NGO are now involved in KZN, and had encountered difficulties with laboratory services resulting in them supporting laboratory equipment purchases. Their impression was also that there is still a huge unmet need in this province.

Summary of treatment numbers by province

	Estimated	Date	Source
WC	11,147	End August	Report
KZN	19,000	Mid-August	Unconfirmed
FS	2,500	End July	Report
Gauteng	20,000	End July	Unconfirmed
NWP	7,578	Mid-September	DoH
LP	5,000	End July	Unconfirmed
MPU	***936***	***January***	***DoH***
NC	1,296	Mid-August	DoH
EC	6,840	End July?	Media
Total	**74,297**		

Discussion on national issues

A discussion followed on national issues related to the roll-out.

- The forum expressed its unhappiness about previous criticism by the DoH of the forum for not providing the DoH the opportunity to present to the forum, and the subsequent failure of the National DoH officials to attend, in spite of 3 senior officials being independently invited.
- Concerns were raised about vulnerable groups, in particular prisoners and refugees. Reports on the refusal of treatment on the basis on patients not having ID books were worrying, and it was queried as to why the department of health had not instituted a back-up system of providing unique identifiers for patients starting ART. There is a lot of work being done by the ALP on the issue of prisoners accessing ART, but it is too early to report properly on these developments.
- It was felt that the JCSMF should be doing more to ensure that health care workers are accessing care when necessary, and that we cannot assume that they are easily able to access care
- Given the discrepancy in capacity between provinces, some members felt that more could be done to harness donor support coherently towards supporting weaker provinces.
- A discussion on accreditation questioned whether it was appropriate for a major health intervention to be subject to national level accreditation prior to commencement. This was not done for other more complex interventions and sufficient controls exist through management, financing and drug supply mechanisms for provinces to control which sites provide the intervention. The system strengthening aspects of accreditation are possible without a formal accreditation process.
- As regards drug supply, there remain many questions about the registration of new drugs and formulations, and the failure to do simple things nationally such as organize blister packs of common formulations to aid adherence. It was also felt that where clinical expertise exists as in some provinces, it would be in the national interest for there to be more operational research on different combinations (eg. the use of tenofovir in first-line to lower the incidence of side effects including lactic acidosis)

- On human resource issues, it was felt that some categories of staff would benefit from improved career paths in the ARV environment, in particular clinical nurses and pharmacy assistants. There was confusion on what the legal constraints are that prohibit lay counsellors from doing the HIV testing in VCT, a frequently observed bottleneck. There is a window in which civil society can comment on the national HR framework and members were encourage to do so, through the ALP who will be making a submission.
- The meeting received the news that the Advertising Standards Authority (ASA) had once again ruled against the Dr Rath Foundation that very day. Members expressed their outrage at the activities of the Foundation and the failure of the NDoH to regulate their activities.

Resolutions

The forum resolved:

- To write a letter to the National Department of Health detailing our disappointment at their failure to attend the meeting in the light of their previous criticisms of the forum.
- To write to the parliamentary portfolio committee on health expressing concern that the briefing to parliament on the comprehensive plan by the NDoH had been cancelled, and that the knock-on effect of this was the failure of the NDoH to provide information to civil society.
- To establish from the deputy president how her office will be continuing to provide leadership to the national response to the HIV epidemic, and request that civil society be part of whatever mechanism she has planned.
- To request a plan from the NDoH to regularly disseminate information on the progress in the provision of HIV treatment, noting the current lack of transparency
- To write to the NDoH requesting clarity on Human Resources Framework.
- The forum calls on medical schemes and the Council for Medical Schemes to participate in the forum and to provide more information on developments in the private sector
- The forum calls on the both the Provincial Government of the Western Cape and the City of Cape Town to ensure that they put patients first in resolving the future of primary care services in the City, and in particular that mechanisms be found to ensure that there are no obstacles to the provision of ART at primary care level to children and TB/HIV co-infected patients. The forum resolved to reflect the extreme frustration felt by service providers at the inability of these authorities to make progress in their deliberations.
- The Forum calls on the NDoH and associated bodies such as the Medicines Control Council to take decisive action against the Dr Rath Foundation and their activities of misinformation, illegal clinical studies, and the sale of unregistered medicines.

- The forum undertook to raise with the NDOH the following concerns about the implementation of the Operational Plan:
    - That the process of accreditation can no longer be justified as a national process, and that provinces should be encouraged to rapidly increase their service platforms where there is willingness and capacity
    - That models of care are required that provide for ART to children and adults together in their communities

Next meeting

November in the Eastern Cape, hosted by IDASA

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