



Newsletter n. 2 – June 2011

CoBaSys - Community Based System in HIV treatment

Dear readers,

This issue of the newsletter follows the mid-term meeting of the CoBaSys partners in Windhoek, Namibia, which focused on the presentation and discussion of the main findings emerging from the Focus Groups organized by the African partners of the consortium and systematized in Reports which are available on the [CoBaSys website](http://www.cobasys.eu). Among the most interesting issues are:

a perceived lack of coordination and interaction among stakeholders in the field of HIV/AIDS intervention that often result in a duplication of roles and initiatives;

the fact that treatment and prevention are considered two different and often dichotomous initiatives, and therefore are seldom part of the same planning structure;

while access to testing is adequate, it is difficult to access ART and CD4 count services in areas far from the main centres and cities;

the specific vulnerability of HIV+ women can be further aggravated by the fact that the majority of interventions target women, which can lead to further discriminations on the basis of gender;

traditional leaders and healers and faith-based organizations are key social groups which should be considered in all the planning activities;

the youth health needs are often different from those of the other groups and should be specifically addressed and targeted.

In this issue, Emidio Gune, Ana Loforte and Alexandre Mate of University Eduardo Mondlane in Mozambique and Fortunate Machingura of

TARSC Zimbabwe present the major findings of the Focus Group discussions held in Manhiça (Mozambique) and in Goromonzi (Zimbabwe) Districts; while Riikka Shemeikka of the University of Helsinki presents the highlights of the mid-term Windhoek meeting. Further information on the project can be found on the CoBaSys website at: www.cobasys.eu

Roberta Pellizzoli, University of Bologna



Focus Group in Maluana, Manhiça District, Mozambique (pics: Francesco Guaraldi)



Participatory Action Research and expert discussions on community-based HIV treatment: CoBaSys Mid-term meeting in Windhoek

The mid-term meeting of the CoBaSys programme was held at Safari Hotel and Conference Center, Windhoek, Namibia on 27-29 April, 2011. The meeting, hosted by the University of Namibia, had several important goals, which were all successfully achieved. These included, for example, presentation and discussion of first results of the work package 2 (WP2) **local focus group research** in Zimbabwe, Malawi, Mozambique, Tanzania, Botswana and Namibia; specifying the activities of the work package 3 (WP3) **model of community based care system** and; planning the next steps of the other work packages, i.e. WP4 (**setting up stakeholder fora**); WP5 (**building up cooperative network EU-Africa**); WP6 (**internal monitoring and quality control**) and; WP7 (**dissemination**). A national **Roundtable on Community-based systems in HIV treatment in Namibia** was organized on the second day of the meeting.

The presentation and discussion of the results of the primary research carried out in Zimbabwe, Malawi, Mozambique, Tanzania, Botswana and Namibia, together with the roundtable discussion, were the most important scientific contributions of the meeting. Primary research was implemented using the participatory action research (PAR) approach as developed by WP2 leader TARSC, the CoBaSys partner from Zimbabwe.

Fortunate Machingura from TARSC presented the results of the research carried out in [Kariba](#) and [Goromonzi](#) in Zimbabwe. Ireen Namakhoma and

Kingsley Chikaphupha from REACH TRUST Malawi presented the results from [Chiwamba](#), [Nkhata-Bay](#) and Mchinji, while Levison Chiwaula from the University of Malawi presented the results from Nsondole. Alexandre Mate and Emidio Gune from the Universidade Eduardo Mondlane presented the results from [Manhiça](#) and Marracuene in Mozambique. The study region of the University of Namibia is Caprivi and a presentation of the results from this area was made by Kenneth Matengu and Pempelani Mufune. Results from [Old Naledi](#) in Botswana were presented by Keshav Sharma and Thabo Seleke. Results from Tanzania were presented by WP2 leader Fortunate Machingura because representatives from the University of Dar es Salaam were unfortunately not able to participate the meeting.

Presentations of the research results from the study regions were very interesting and provoked lively discussions. Other CoBaSys work packages are largely building on the results of this primary research. The next steps of this work package include creating a synthesis of its results.

During the midterm meeting, a **National Roundtable on Community-based systems in HIV treatment in Namibia** was organized. National roundtables are part and parcel of the WP3, and they will be organized in all of the African partner countries. The aim of the CoBaSys roundtable in Namibia was to share existing experiences of community-based care system in fighting HIV and AIDS in this country and in particular in Caprivi. The roundtable involved different stakeholders such as representatives of the Ministry of Health and Social Services, UNFPA, NGOs, and local communities from Caprivi, among others. The main focus of the presentation of the Caprivi community



representatives, Ms. Agnes Mwilima, Mr. Joseph Mbucho, Mr. John Mafuta, Mr. Eugene Muluku and Mr. Marius Manepelo, were the challenges in **community and home-based care (CHBC) and orphans and vulnerable children (OVC) and the best practices from the Caprivi Region in these fields.** Dr. Justice Gweshe from the National HIV/AIDS & STI Control Programme, Ministry of Health and Social Services, gave a presentation on **comprehensive health care system and the challenge of decentralization of service provisions.** This presentation included information on decentralization policy, District Health System and National health policy framework. In his presentation, Dr. Gweshe also described service delivery model and its challenges in Namibia. Mrs. Dorkas Haiduwa-Kapembe from Namibia Red Cross Society gave presentation on ART dependency and sustainability, including e.g. the principles of home-based care provided by the Red Cross, volunteers tasks, treatment adherence, and challenges and recommendations for the Namibia Red Cross Society's community-based health care. Ms. Ireen Namakhoma from REACH TRUST gave a presentation on **defining a community-based model** on the basis of the experience from Malawi. Report of the Roundtable Discussion and part of the presentations above will be soon available on the CoBaSys website.

The mid-term meeting was also an important forum for planning the next tasks of the project. All the work package leaders presented their future plans, and the timetable of the project was updated. Associate partner [European AIDS Treatment Group \(EATG\)](#) introduced their activities, and planning for training of project members started on the basis of training needs assessment made by the University of Namibia

and the University of Helsinki. Out of the initiative of University of Bologna, a Publication Committee was selected to plan an effective publication policy for the project.

Besides the formal meeting, in a project like CoBaSys, which consists of partner organizations located across Europe and Africa, it is of vital importance from time to time to meet each other and discuss in a creative and informal atmosphere. Also in this respect the meeting was successful. On behalf of all the participants, I wish to present many thanks to the project coordinator, CUSCOS at the University of Modena e Reggio Emilia, and the hosting organization, University of Namibia, for an efficient, pleasant and extremely well-organized conference.

Riikka Shemeikka, University of Helsinki



CoBaSys partners at the Windhoek mid-term meeting

Major findings of Participatory Action Research in Manhiça District, Mozambique

The University of Eduardo Mondlane (UEM) is implementing the Community-based systems in HIV treatment (CoBaSys) programme to empower communities to support antiretroviral delivery programmes for patients with HIV infection in east and southern Africa (ESA).

The project primarily focuses on building solid community-based systems that support the HIV treatment to benefit most vulnerable social groups at primary care level.

The study employed qualitative techniques with varying Participatory Research and Action (PRA) approaches and tools to triangulate the methodologies and ensure validity and reliability of data. The study units included men, women, young people, and elderly, people living with HIV/AIDS, health workers, opinion leaders, leadership and other key stakeholders. The study was carried out in Maluana, Manhiça district, and it entailed a 3 day PRA research meeting.

The Maluana PRA research participants were drawn from Ministry of health and Child Welfare (MOHCW), local authorities, health workers, community representatives, people living with HIV/AIDS (PLWHA) and other key stakeholders

In Maluana there are several organizations that provide home-based care to people with serious or chronic diseases, including AIDS. This activity is shared by religious organizations in the communities. Community leaders do sensitize people to adhere to testing services and comply with the treatment prescribed in hospital.

Overall, participants suggested that young people, adults, elderly and children are the ones who are at greatest risk of HIV infection in their respective order. Women and girls show that they are

vulnerable because their husbands, who work in neighboring South Africa, return from the mines infected and transmit the virus to them. Young men and women were reported to be highly vulnerable due to multiple sexual partners with whom they do not use condoms.

Participants highlighted that the scarce commitment of men to HIV prevention is associated with culture and traditional norms. Usually, men refuse to use condoms. Men allege that in African tradition they are the heads of the households and their word is the law and women must be subdued. Therefore, women have fewer possibilities to negotiate their sexuality with men. On the other hand, married women refuse having sex with their husbands when they use condoms, alleging that men had sexual relations outside. Also, many men are afraid of revealing their HIV positive status because they fear losing their partners and being rejected by their social group. Insufficiency of health personnel, high cost of medicines, and lack of medicines are their priority problems. Youth asserted that the local health centre lacks of equipment and medicines. The other health centre located in Maluana village is far from the community and there is a lack of transports and money to reach it. This is aggravated by the poor condition of the roads. Opinion leaders ranked the lack water, lack of HIV testing packs, lack of food as key challenges. They stressed that “water means life” and they need support to bore water hole supplies.

This research identified recommendations that policy should consider in defining a comprehensive community-based model for HIV treatment, support and care amongst PLWHA and those affected. These include the recommendations at community level and in the health system.



Recommendations for community action:

- i. Community campaigns on education and adherence to treatment, change in gender norms and community mobilization for elimination of stigma and discrimination related to HIV and AIDS
- ii. Information on treatment: medicines must be given in local languages to facilitate knowledge and adherence to treatment
- iii. Build capacity of NGOs to manage programs and develop networks and support for people vulnerable to HIV and AIDS.
- iv. Promote the provision of medical care and drugs supplies at health posts.
- v. Develop training programs on HIV prevention, modes of transmission and life skills among local leaders.
- vi. Promote inclusiveness among leaders to participate in planning process and programs to HIV and AIDS treatment.
- vii. Mobilizing solidarity groups and their leadership to provide support to PLWHA.
- viii. Develop strategies to reach and work with women and men who have been previously excluded in local programs to fight HIV and AIDS.

Recommendations for health system actions:

The Ministry of Health needs to implement measures to ensure knowledge and adherence to ARV treatment at district level proposed in the strategic plan (National AIDS Council, The National Strategic Plan on HIV/AIDS 2005-2009) such as:

- Undertake information, Education and Communication activities targeting different population segments, adapting the message and the vehicle to target audience and make use of mother tongues. Particular efforts

should be made to ensure that messages reach and make are female audiences;

- Make all sectors in general, and the public sector in particular aware, by promoting an increase in knowledge about HIV/AIDs, in population segments they cover.

Emidio Gune, Ana Loforte, Adérito Machava, Alexandre Mate, University Eduardo Mondlane



Focus Group in Maluana, Manhiça District, Mozambique (pics: Francesco Guaraldi)

Strengthening community health systems for HIV treatment support and care. The case of Goromonzi District in Zimbabwe

Improving health outcomes is central to community system strengthening, more fundamental in combating HIV and accelerating the goals for HIV treatment in low resource settings. Often, however, community systems for HIV treatment in areas with minute resources seem a distant, even abstract aim. This should not and need not be the case given that the understanding, evidence and nuanced knowledge of what constitutes a community-based system for HIV treatment, support and care is growing and is now available. This article will deepen understanding and stimulate fresh thinking

among stewards of health systems, health system researchers, community-based partners and partners alike.

The article will focus on a) the research findings, b) a discussion and c) recommendations at (i) community level (ii) frontline health system (iii) interface between community and health system from the research conducted in Zimbabwe, Goromonzi District. Principally, we understand and agree that communities are not homogenous entities. However, we also recognise that the general characteristics that define the community health system in ESA countries are closely related¹. Therefore, the recommendations can be inferred and interpreted in similar settings.

Zimbabwe - Goromonzi District

Zimbabwe is one of the Sub-Saharan African countries most hard hit by the HIV and AIDS pandemic with exceptionally high levels of HIV prevalence in the past and significantly lower levels at present. The HIV prevalence rate declined from 24.6% in 2003 (MOHCW 2005) to an estimated 13.7% in 2009 (MOHCW (2009)). The highest number of PLWHA ever reached in Zimbabwe was an estimated 1.8 million (ranging from 1.6 - 1.9 million) at the end of the 1990s (UNAIDS June 2010). Estimates of adult mortality show that in 2010, Zimbabwe had one of the highest rates of pre-mature adult mortality in the world, largely due to AIDS. Annual mortality increased from 244 per 100,000 in 1990 to 725 per 100,000 (MOHCW 2007) among adult women 15-49. However, AIDS-related mortality is following a decreasing trend. This decreasing trend, first of such kind in Southern Africa (see figure 1) has been attributed to 1) decreasing

urban (from over 6% in the 1980s to an estimated 1.7% in 2005) and rural population growth rate (from over 3% in the 1980s to a negative growth rate of -0.1 by 2005, UN data) 2) out-migration and deaths due to AIDS cancel population growth hence the stagnation during the late 1990s and early 2000s (Gregson et al. (2010) and 3) increase in number of people on ART.

The number of people currently on ART increased from 85,000 to 215,000 between December 2008 and December 2009 (NAC 2009) leaving a treatment gap of about 340,000. However, based on the 2009 WHO recommendation of initiating ART at a CD4 count of 350, an estimated 570,000 adults were eligible for ART in 2009 (this translates into ART coverage by end 2009 at 38%).

The HIV prevalence levels in Zimbabwe are homogeneous across provinces as well as between rural (17.6%) and urban areas (18.9%). Goromonzi District, which falls under Mashonaland East Province, has a general prevalence of 18%.

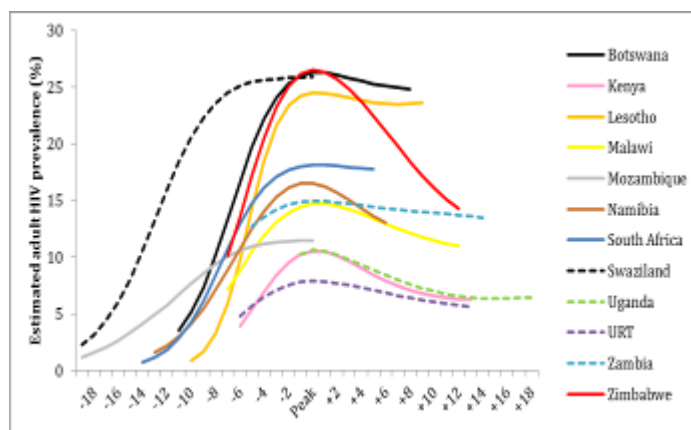


Figure 1

Findings

Social and economic differential in HIV treatment

There are **socio-economic differentials** that affect risk and vulnerability to HIV/AIDS and that have an impact on uptake of available services for treatment and care in Goromonzi District.

¹ In their organisation, orientation and resource provision. Hence the challenges faced by communities in accessing, accepting and contacting available resources can be generalised. See COBASYS PAR reports www.cobasys.eu

Informal market, petty trading, seasonal farm casual labour is more dominant form of economic activity for the rural population. Other sources of income noted included remittances, formal employment and vegetable sales. The relative availability of these economic activities was used as proxy for access to income and food central to treatment access (transport costs and other out of pocket costs) and treatment adherence. Transport was noted as the major household expenditure among PLWHA. This was attributed to poor road networks and transport costs to Makumbe district Hospital which operates as the only ART site in the district.

Priority health problems of PLWHA

The priority social and economic determinants at household, community and system level that facilitate and block access and uptake of HIV resources were specific to social groups. **Women** highlighted that **long distance to accessing ART facilities and services and gender inequality as their** top problems. They noted that gender **inequalities** limit women's access to HIV/AIDS treatment, care and support, including ART. HIV positive women face stigmatization and are more likely than men to be blamed, stigmatized and abandoned by their families. This was reported to cause treatment defaulting for those already on treatment and refusal to get on treatment due to fear of stigma for those not on ART. The insufficient coverage and unequal geographic distribution of ART services increases vulnerability particularly in remote and marginalised wards such as Gutu and Mwanza which were reported to have lower levels of knowledge about treatment literacy. Thus, **treatment** adherence remains unsatisfactory, also compounded by long distances that need to be travelled to get to the ART site. Transport costs

to the clinics are prohibitive for the majority of these rural populations.

The underlying, intermediate and immediate causes of health needs of PLWHA

While the immediate causes of problems varied, the intermediate and underlying causes remained generally similar across social groups. Deep-rooted structural poverty, arising from such things as gender imbalance, lack of access to services, marginal agriculture, social disruption and fragile political environment were reported to cause vulnerability to the ability to adhere to treatment, and limit opportunity to participate in community based treatment support and care activities. Findings suggest that the experience of HIV/AIDS is likely to lead to an intensification of poverty, push some non-poor into poverty and some of the very poor into destitution. In turn, poverty was observed to disrupt treatment, undermine opportunity to integrate HIV treatment services and exacerbate the impact of the epidemic.



Focus Group in Goromonzi District (pic. Fortunate Machingura)

HIV/AIDS responses in health services coverage

In order to qualitatively interrogate the health service coverage, five domains of coverage were expressed in terms of availability, accessibility, acceptability, contact and effective coverage.

While human resources, drugs, equipment, sundry, infrastructure HIV and HIV support services where available it was noted that they were not adequate relative to the populations they were serving. Findings further highlighted that dimensions of access vary in predicting an individual's likelihood to receive care; with implications in improving health outcomes. For use of services, structural issues such as transportation have measurable and surmountable danger regarding improvements to enable access. Standing out was the distance from ward facilities to Makumbe district hospital. Makumbi Mission district hospital is more than a 100km from the wards such as Chikwaka, Rusike, Gutu and Gosha. Patients take too long to get there should they have money to get to the hospital. Those who do not have money are forced to delay seeking health care. Patients on ARVs are forced to default from their treatment.

Some patients are forced to seek health care services from neighboring Musani Mission Hospital in Murewa District. This has negative implications on planning and resource allocation for Goromonzi District (ARV supply will be less than what is actually needed). Opportunity costs are also considered and most continue to die from preventable opportunistic infections due to long distance (patients reported a preference to work in their crop fields than spend one and half days trying to get cotromoxazole). Some opt to buy drugs on the streets, most of which are falsified counterfeit drugs.

Time spent before contact with service was long increasing costs on out of pocket payments as a result of lodging, food and transport. The time spent waiting for service is further elongated by the number of ARV patients waiting to receive their treatment. This is so due to the congestion emanating from Makumbe mission being the only ART site in the whole District of more than 20

wards. The following quote from a participant corroborates this assertion (my translation): "I want to thank you for conducting this research work here in Goromonzi. The actions that we shall agree on shall be implemented by us, and TARSC with its partners will support is to implement action that brings change to our current health problems, is this not what you are calling Action Research? We want ARVs to be easily accessible in our local clinics- at Mwanza, at Kowoyo, at Rusike Health centers, not to continue with boarding two-three buses to get medication, sometimes when you get to Makume mission, you are told to go to Marondera for CD4 count. This is too expensive for us, surely can we do this?"

Acceptability coverage barriers that were highlighted included language barriers, degree of trust by communities on health care providers, health worker-community interactions and the location of the health centre. In particular, Health worker community interaction was observed as a challenge with propensity to flaw acceptability coverage of AIDS resources. For instance, it was noted that some health workers share patient privacy information with the public, come to work late if they (Health workers) open the health facility at all, and selling counterfeit medicines at their homes for patients. While the Ministry of Health has specific mechanisms to ensure performance management and public integrity management of public resources, participants expressed concern over the extent to which and nature at which such conduct issues were being dealt with and managed.

Barriers associated with **contact coverage** mostly included provider compliance. In some instances patients are informed that ARVs have expired (contrasting with instances where patients are told drugs are not there and some patients succumb to opportunistic infections before they get enrolled on the national ART programme). In



such cases patients noted that Health workers still ask patients if they would want to use the expired drugs. The lack of health provider compliance with National Health regulations raised a lot of questions on compliance, trust and diagnostic accuracy. The increased trend in defaulters and lack of adherence were associated with drug stock outs and lack of skill within the health system to deal with patient ART side effects. One participant highlighted that ART side effects continue to proliferate effects of stigma and discrimination: “The greatest war is on these big tummies that we carry, you see- we move around with sticking tummies like pregnant women due to the ARVs we take. These side effects continue to make us vulnerable due to stigma associated with this”.

Community systems and mechanisms for clinical mentoring in HIV treatment

There was a general acceptance that practising clinicians with strong teaching skills and with time to mentor less experienced health workers in the administration of HIV treatment and management of AIDS were not available. Further, to this there is no training curriculum to show the direction that was supposed to be taken by the mentors should they be available to conduct the training. This lack has been one of the reasons attributed to the absence of decentralized delivery of HIV care, antiretroviral therapy and prevention with high-quality care at all levels. However, and important too was the acknowledgement of supportive supervision, a critical component of capacity-building for case management.

Organisation of primary care patient flow approaches in HIV treatment

Understanding of patient flows within health facilities provided an in-depth appreciation of flaws that exist within health facilities for delivering HIV treatment. These flaws were

observed to resonate with long waiting times and health worker –patient interaction. Due to low staffing levels compounded by shortage of trained man power, patients spend long hours waiting for service (and long queues). These waiting hours are often characterized by patients with empty stomachs, frustrated and angry for slow service. By the time the patient gets contact with the health worker they are angry, hungry and tired leading to vindictive communication. Also, the tagging of the OI clinic at ART sites was observed as a propeller of stigma and discrimination in its own right. Other issues common at each point of the patient flow included power outages, machine/ equipment breakdown and staff absenteeism .



Participants of the Focus Group in Goromonzi District, Zimbabwe (pic. Fortunate Machingura)

Community resources, institutions and actors that respond to HIV/AIDS

Goromonzi described participation of stakeholders working in HIV issues, organizations and institutions alike as tokenistic. The tokenism in participation condemned is recognizable in that acknowledgement of the need to participate appeared as an end in itself. The call for all stakeholder participation in fighting HIV and integration of services from different stakeholders was tagged “rhetoric and cliché” in nature. The lack of support from line ministries to the MOHCW to support HIV and health related

programmes at community level were noted. An example given showed that while nutrition for PLWHA is a MOHCW issue, it was equally a Ministry of Agriculture issue. The argument given was that while a lot resources every year are evidently channelled the mechanization and agricultural support, there was nothing substantive for health, let alone HIV. Most of the resources for HIV/AIDS, particularly HIV treatment were reported to be financed through the Global Fund, funders and donors alike. Even with these donors, communities observed that the funding schemes on HIV treatment, support and care were often parallel lacking integration with a bias on HIV treatment. While policy stakeholders and organisations working on health do appreciate the fundamental need to integrate services, it seems there is a sudden plague that lifts the same institutions to want to meet set target goals than to address the problem more holistically. Equally, the integration of resources now looks like a war that has been wedged, unfortunately with an army ill prepared to face the consequences of war. Thus it seems as if the acknowledgement of the need to address HIV issues holistically is only tokenistic. Indeed, this is dangerous and hypocritical gesture, not a constructive first step.

Discussion

Overall, stigma and discrimination is deeply rooted and entrenched in operational systems both within the health system and at community level. PLWHA are still unarmed, unorganised, disunited and most importantly psychologically and morally unprepared for the likely responses from their communities on their HIV disclosure. Though there was consensus that there is to some level a sense of desperation that had prepared this social group with courage to commit seriously to fighting stigma, they were however not willing to

sacrifice ‘*confidentiality*’ with no prospect of victory.

Whether tokenism in HIV resource integration at community level is a phenomenon that needs further investigation both at national and global level or not is debatable. What is clear is that these resources need to be channelled where greatest need is. Thus the goal for equity and people-centred health systems still need pursuance not only by communities in charge of resources but also governments responsible for resource allocation. Certainly funding partners, aid institutions and partners alike need to collectively plan to support community based systems in HIV treatment.

Recommendations

To this end, the PAR action research identified recommendations that policy should consider in defining a comprehensive community based model for HIV treatment. These recommendations have been framed into three main health system domains for HIV treatment:

The community level

- i. NGOs can support Ministry of Health by providing the resources needed for comprehensive AIDS services at the community level. However, their contributions should be channelled through the (coordination of) Ministry of Health.
- ii. Massive campaign and treatment education should be coupled with campaigns against stigma and discriminations

The frontline health system

- i. Government should not rely on international funding assistance such as Global fund for AIDS, TB and Malaria because it is not reliable. Not qualifying for funding undermines progress in universal coverage



and availability of ARVs. Therefore government should

- ii. Increase the national fiscus and pool resources towards health to increase allocation to HIV treatment attention, support and care
- iii. Promote local drug manufacturing industry to manufacture generic drugs (that are cheaper and would increase availability coverage)
- iv. Government should have control over international donor assistance such as Global fund. Global fund fragments the health system and creates systemic disparities in income amongst the Health Workers
- v. Reducing out-of-pocket payments by removing public sector user fees
- vi. Reduce other health care costs (transport costs) by making clinics ART sites

The interaction between community and health system

- i. Strengthen capacity of lay health workers such as Village Health Workers and community Home based Care programmes to facilitate uptake of treatment, adherence and treatment literacy

- ii. Global Fund resources including other assistant funding should be channelled through government Ministries, particularly the MOHCW. Furthermore, non state actors including NGOs should support the Government in enforcing public accountability mechanisms to ensure effective use of these resources.

Fortunate Machingura, TARSC Zimbabwe



Focus Group Discussion in Goromonzi District
(pic. Fortunate Machingura)

For more information on the CoBaSys Project please visit the official website:
<http://www.cobasys.eu>

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This project is funded under the [ACP Science and Technology Programme](#) - Grant Contract N° CoBaSys FED/2009/217-058

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