

HATIP

HIV & AIDS Treatment in Practice

Issue 175 | 17 March 2011



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Spurring community engagement to ensure the proper implementation of the Three I's for TB/HIV

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This edition of HATIP was kindly supported by the HIV department of the World Health Organization.

The AIDS and Rights Alliance of Southern Africa (ARASA)/World Health Organisation (WHO) Three I's for HIV/TB Advocacy Workshop

"We believe that advocacy is essential to ensuring greater access to services by helping governments to understand WHO recommendations and encouraging them to meet their commitments," Lynette Mabote, advocacy programme manager for the AIDS and Rights Alliance of Southern Africa (ARASA) said at a recent joint meeting between WHO and southern African civil society organisations.¹

The meeting, held December 7-10 2010, Johannesburg, South Africa, focused on new community-led initiatives to move recently revised WHO HIV/TB policies into practice.

More specifically, the meeting was workshop to develop an advocacy toolkit to better communicate to local audiences recent WHO guidance regarding the Three I's for HIV/TB (described in more detail below) — and also served as a forum to discuss how civil society and WHO can best work together to develop and implement policies that benefit the community.

"Community stakeholders need to start taking ownership of the policy changes at community levels and use existing mechanisms and networks to ensure that changes required are also translated into action on the ground," said Mabote. "Community-driven objectives will see much more streamlined implementation of the guidelines than those that are top down."

The gathering was one of the latest meetings in which WHO, and other multilaterals, such as UNAIDS, have moved beyond simply acknowledging the importance of involving the community when making policies that affect them. Rather, WHO has begun to explore ways to support and provide technical assistance to activists and civil society organisations as partners who are advocating for policy, translating key policy messages for local settings, developing training and educational materials, and even, in some cases, evolving into implementers and service providers.

For instance, almost two years ago, WHO's HIV Department launched a consultation with activists and organisations representing people living with HIV which gave the community unprecedented input into the development of WHO's revised ART guidelines.² These guidelines recommend standards of care in resource-limited settings on a par with the rest of the world, promoting earlier HIV treatment with safer drugs.

Subsequently, WHO, UNAIDS and the International AIDS Society worked with community representatives to develop Treatment 2.0, putting human rights and community engagement at the heart of the new proposed treatment paradigm that emphasises both the treatment and prevention benefits of antiretroviral treatment (ART).³

According to the meeting report and advocacy documents that have since been released by UNAIDS, the success of Treatment 2.0 hinges on community engagement.

Without treatment activism, better and more affordable treatments and diagnostics called for under the Treatment 2.0 model will not become available. Furthermore, the expansion of treatment envisaged in Treatment 2.0 means that the community will increasingly be relied on as service providers in the ART roll-out.

Engaging the community in the delivery of the prevention, testing, treatment and care services should expand the reach and reduce costs of these services — and may, indeed, be the only way that overstressed and resource-poor health systems will ever reach the goal of universal access.

Similarly, in the past few years, WHO's Stop TB Department has also been emphasising the importance of community engagement at all levels in policy guidance (as described in the Stop TB Strategy and 2008 Guidelines on Community Involvement in Tuberculosis Care and Prevention), as well as the key role of civil society in the delivery of services on the ground).⁴

In 2010 the STOP TB Department held a meeting in Geneva with representatives of civil society to find practical ways to put community engagement into practice, to exchange experiences and share innovative ways of working together to strengthen efforts for prevention, care and control of tuberculosis (TB) worldwide. More recently the STOP TB and HIV Department worked together with civil society input to produce its new IPT/ICF recommendations.

It is where HIV and TB intersect that community engagement may be most needed — and it is the community of people living with HIV who have the most to gain by demanding, and in some cases, providing services to improve early detection and treatment of TB cases and to reduce their risk of tuberculosis — particularly in the southern Africa region.

Two epidemics, one public health nightmare

High rates of HIV, compounded by an over-burdened, under-resourced health care system; inadequate nutrition; poor access to housing leading to overcrowding; and unresponsive governance have allowed tuberculosis (TB) to keep a strong footing in the region's relatively resource-limited countries. The rise of drug resistant, multi-drug, and extensively drug-resistant tuberculosis is of acute concern.

The HIV epidemic fuels the TB epidemic. People living with the virus are between 20-37 times more likely to develop active TB. In 2009, TB was the leading cause of death among people living with HIV. Access to life-saving anti-retroviral therapy (ART) and TB testing and treatment remains scarce in under-resourced settings such as those in southern Africa, especially within rural areas. In 2009 there were an estimated 910,000 HIV-positive TB cases in Africa, which represented 76% of the total global HIV TB burden.

In response to the rise in both epidemics, the World Health Organization (WHO) has published a series of guidelines on HIV and TB prevention, treatment and care to help guide governments, civil society, and health care workers (HCWs) in adequately addressing a burgeoning health crisis.

WHO recommends three key public health interventions, namely the Three I's for HIV/TB (TB infection control (TB IC), intensified TB case findings (ICF), and Isoniazid Preventive Therapy (IPT)) in addition to earlier ART to reduce the burden of TB.

Central to this work is the need to emphasise that the Three I's for HIV/TB should be core components of HIV prevention and care

and should be the primary responsibility of AIDS programmes and HIV service providers.

In addition, the Three I's for HIV/TB can be woven into a TB prevention package alongside the provision of ART for people with HIV.

Despite this, uptake and implementation of the Three I's for HIV/TB remains poor across the region, with TB and HIV services often being distinct and disparate.

While many SA countries have national HIV/TB coordinating bodies, district and/or facility implementation is limited. Knowledge and implementation of infection control strategies, including critical administrative interventions such as triage (first attending to people with cough so that they don't mix with people without TB in the health facilities) and simple environmental controls such as opening windows to allow for cross-ventilation in houses and clinics, remains low amongst both health care workers and the general population, as was reported by several participants at the meeting. PLHIV are still not routinely screened for TB, especially within congregate settings, and contract tracing is rarely done.

Turning policy into practice: the ARASA/WHO Three I's for HIV/TB advocacy toolkit workshop

ARASA welcomed the recent detailed guidance on the Three I's for HIV/TB from WHO, including the 2009 WHO Policy on TB infection control in health-care facilities, congregate settings and households (the TB IC guidelines) and the new 2010 WHO guidelines for intensified case-finding (ICF) and IPT for people living with HIV in resource-constrained settings (the ICF/IPT guidelines). This guidance represents an important and positive step to move the Three I's for HIV/TB forward at the country level.

But ARASA also noted with concern the substantial gulf that remains between policy and practice.

ARASA believes that part of the problem is that these guidelines, which are lengthy and complex, are written for the most highly trained public health authorities and not really targeted to lay people, or primary care providers such as nurses or community-based health care workers.

"Guidelines such as about the Three I's for HIV/TB are simply not digestible enough to be easily translated into on-the-ground work," said Lynette Mabote. In addition, she said the lack of certainty on some guideline points, such as exactly how long IPT should be given, potentially contributes to low implementation.

It should be pointed out here that the guidelines strongly recommend that people living with HIV should get at least 6 months of IPT. However, there are other situations — such as in settings where the risk of TB transmission is high among people living with HIV— where WHO gives a 'conditional' recommendation to provide at least 36 months of IPT.

It is this latter 'conditional' recommendation (and others like it) that have led to some confusion. The problem is not that the guidelines are unclear, but rather that the available evidence for some recommendations isn't as strong or is conflicting. Furthermore, while the new manner in which the WHO now presents its guidelines makes this very clear, inadvertently, this may also make some of the recommendations sound less definite than they would have in guidelines past. Therefore, this conditional recommendation is one that requires local officials or organisations to make a decision about whether to act on it, based upon local conditions.

However, the regional and country WHO offices are tasked with providing technical assistance to help countries determine how best

to convert international normative guidance into local policy. They should also provide assistance to develop standard operating procedures and training materials to implement the policy.

At the meeting however, activists noted that for one reason or another, these activities don't always seem to happen in a timely fashion. Furthermore, over the course of the meeting, it was often expressed that local country authorities are resistant to engaging the community in the HIV/TB response, despite WHO policy; and the community felt that assistance from WHO's in-country/regional offices could help negotiate their increased involvement. (A similar need was noted [by the community at the Stop TB Community meeting](#)).

Consequently, the community often has to take the lead in publicly explaining, advocating and designing training materials and providing support services to facilitate implementation of new WHO policies in their own countries, sometimes with relatively little support. While some of these needs are financial, community groups also need logistical support and technical assistance.

Responding to these concerns, in what is hoped to become a pattern of increased support and technical assistance for the community, the WHO partnered with ARASA to host a week-long workshop on the Three I's for HIV/TB. According to WHO's Dr Reuben Granich, the meeting is one part of WHO's two-pronged guidelines dissemination process — community engagement and engagement with local TB and national AIDS programme controllers.

The goal of the workshop was to find ways to adapt the guidelines for local audiences, to make it easier to explain to over-stretched health care workers, civil society organisations, government officials, and the general public to what is being recommended and why.

The gathering brought together 20 civil society participants from across the region to brainstorm about what tools and information should be compiled into a Three I's for HIV/TB advocacy toolkit, to be used by stakeholders throughout southern Africa in order to boost implementation efforts. The tool kit will ultimately be tailored for a variety of parties, including health care workers, civil society, government, and patients for use in different settings across southern Africa.

The process employed by ARASA, WHO and the other organisations present, could prove a useful model for other NGOs and civil society organisations wishing to implement the Three I's for HIV/TB in their regions.

The workshop was structured to focus heavily on group work, supported by presentations on the science, policy, and politics of TB and HIV. Key presentations were made by the WHO, ARASA, the Treatment Action Group (TAG), and the Botswana Network on Ethics, Law and HIV/AIDS (BONELA), ensuring that participants had a strong understanding of the Three I's for HIV/TB, advocacy strategies, and TB and HIV policy and science. The amount of time dedicated to the presentations was kept to a minimum, allowing a majority of participants' time to be spent in small groups of four to five working on a variety of scenarios. Each scenario focused on one aspect of the Three I's for HIV/TB, and required groups to form key advocacy strategies and intended outcomes, including timeline, target groups, communication messages and strategies, necessary resources, and potential partners. From this group work, major implementation barriers as well as opportunities emerged. These discussions will form the crux of toolkit content.

What are the new IPT guidelines?

On December 1 2010, World AIDS Day, the WHO released a new set of guidelines for intensified TB case-finding and isoniazid preventive therapy for people living with HIV in resource-constrained settings, such as southern Africa. IPT use has been proven to reduce cases of active TB by up to 64% when taken by people who have latent TB.

Despite being recommended for those infected with the virus since 1998, IPT use remains low, in part because of structural constraints such as lack of capacity to perform tuberculin skin testing (which is no longer required in the current guidelines), lack of patient education, and health care providers' resistance to prescribe the drug, as well as countries' slow efforts to include IPT in national TB and/or HIV policies.

In addition, there has been low patient literacy on the issue, as many community-based organisations themselves had been reserving judgement about who should take the drug until high quality data became available. There is great variation in IPT use within the five countries represented at the workshop, with most only providing IPT through pilot studies or restricting access to specific populations.

But several ICF and IPT studies have now been conducted in people living with HIV in resource-limited settings. With scientific evidence mounting that IPT is safe and effective save for exceptional cases, the WHO now strongly recommends that every person living with HIV who does not have active tuberculosis be placed on at least six months of IPT, regardless of whether they are pregnant, have previously been infected, are taking ARVs, or are young (it is not recommended that those under 12 months be given the prophylaxis, pending more research). These new guidelines greatly expand the number of people eligible for receiving IPT.

In areas of high TB and HIV prevalence, such as those in southern Africa, WHO conditionally recommends giving people living with HIV who do not have active TB at least 36 months of treatment, depending on the local context.

The new ICF/IPT guidelines call for symptom-based screening of people living with HIV to ensure they do not have active TB before taking IPT. If a patient does not present with a cough, fever, night sweats, and/or weight loss, it can then be assumed that they do not have active TB and can be therefore placed on prophylaxis treatment. If patients do present any of these symptoms, however, further tests are required.

Participants at the Three I's for HIV/TB workshop noted that while these guidelines in theory mean that more people could receive the treatment, the community would also need to find ways to address major structural concerns that may inhibit greater uptake. Just as a shortage of health care workers, drug supply interruptions, lack of clinics, limited patient education, and problems with transportation all inhibit access to current health care services, the same structural problems are likely to hinder the scale-up in access to IPT. Additionally, many health care workers remain sceptical of IPT and wrongly associate its use with the development of drug-resistant strains of the bacterium.

But starting with the tool-kit, community-led initiatives may offer innovative solutions to many of these challenges. Education efforts led by community organisations may be the fastest way to improve HIV/TB literacy among patients and even among health care workers.

Community-led monitoring and evaluation (M&E) could keep tabs on drug supply, service uptake, and programme performance, while community engagement in service delivery could improve

adherence and reduce the burden of patient management and follow-up at the clinic level — just as the community is facilitating the roll-out of ART.

Additionally, greater advocacy can encourage governments to expand access to IPT as part of a comprehensive package of HIV and TB treatment and care, and to launch general education campaigns that inform populations about the potential benefits of IPT.

[See HATIP #170 for more on the guidelines](#)

Key workshop goals

“The process of both meeting with civil society and creating a toolkit for multiple stakeholders at the same time is important for WHO, and WHO was “very excited to explore this approach,” said Caoimhe Smyth, a consultant for WHO speaking at the workshop. Workshop participants expressed an interest in discussing and targeting the following issues and exploring potential solutions through the workshop and resulting toolkit.

How WHO works in general, and specifically how its guidelines such as those relating to the Three I's for HIV/TB, can be better integrated into country-level work

Participants were especially interested in investigating how the WHO and civil society can work more closely to ensure proper implementation and roll-out by both government and other organisations, such as NGOs, with the work of the WHO complementing that of civil society and visa versa (what Smith referred to as “push” and “pull” advocacy). Greater communication between the two players was expressed as a key goal.

How to do more with less

Tengetile Hlophe of Swaziland stated that given persistent and severe budget constraints, she hoped to learn “how to make the biggest impact with a little amount of money” — what Paula Akugizibwe of ARASA termed “advocacy on a shoestring.” From the outset of the workshop, all participants noted frustrations with attempting to do local, national, and regional advocacy with very little time and money. (Note, at the STOP TB Department/civil society meeting there were discussions of [some potential funding opportunities offered by TB Reach](#) — which is funding community-based organisations working to improve early TB case detection — as well as technical assistance for community based organisations writing grants requests for the Global Fund). While participants aimed to discuss how to procure resources for their work, they also hoped to learn how to be more effective with less.

How to develop a stronger, proactive relationship between government and civil society

Participants aimed to learn strategies to get government on board, prompting adequate responses and reducing the burden on civil society to fill the current gaps in services and knowledge. ARASA's Akugizibwe also encouraged civil society participants to consider how they could assist with implementation, monitoring and support of the Three I's for HIV/TB regardless of government policy and practice.

“We need to think about what we can do to make these changes happen, rather than just waiting for governments or the WHO to step in. What can we do on our own?” she said.

How advocacy strategies can become more patient-centred and grassroots-oriented

Workshop participants noted that the most effective advocacy strategies are those that are patient-led, with those in need of services at the forefront of demanding them. Participants aimed to

discuss how to increase patient access to information and patient empowerment within advocacy efforts.

To learn more about the science behind the Three I's for HIV/TB and improve their own treatment literacy

From the outset of the workshop, several participants expressed interest in learning more about the science behind the policy. Said Cindy Kelemi from Botswana, "we need to know what the Three I's for HIV/TB are and how we can use them in order to make sure that patients know this." While nearly all participants knew about the guidelines, they noted that their understanding of why the guidelines were made and what scientific research helped to form them was relatively limited. Participants said that greater access to information was necessary for all stakeholders in order for effective advocacy to occur.

Sharing and learning from best practices within the region

Participants were eager to learn from each other about what has and hasn't worked in terms of advocacy, implementing, monitoring and support efforts and resulting outcomes.

Challenges for TB/HIV integration in southern Africa: perspectives from civil society

It is important to identify challenges and barriers impeding care in order to develop the tools to dismantle them. So in the weeks preceding the Three I's for HIV/TB workshop, participants were asked to fill out a questionnaire regarding implementation of the WHO guidance on the Three I's for HIV/TB, access to HIV, TB and other health services, and major barriers impeding care. The following responses were listed as major barriers to uptake of the Three I's for HIV/TB in the region — and these issues came up repeatedly in discussions and group work throughout the week.

Too few health care staff and an over-burdened health care sector

The most obvious and consistent problem presented throughout the surveys and workshop was the lack of adequately trained health care staff, clinics, and access to necessary technologies such as testing facilities and essential medicines.

Clinics that have only a handful of nurses and one or two doctors are common. Many communities are serviced only by one or two hospital or clinics, or, in rural areas, the closest health care provider exists outside of town, making it difficult to access, especially given many people's limited income and limited access to transport.

Drug stock-outs are far too common, with Swaziland, Botswana and Zambia all reporting interrupted supplies within the last year. Similarly, basic tools like N-95 masks are scarcely found in health care settings.

Represented countries have very few laboratories for the population, especially in rural areas, drastically diminishing diagnostic ability. Mozambique, for example, only has one national reference laboratory and two regional laboratories countrywide.

Structural concerns beyond public health interventions

Several major structural concerns that stretch far beyond TB and HIV control, and which affect many aspects of peoples' lives, were highlighted. Over-crowding and inadequate housing means that interventions like infection control are often rendered largely useless.

Several participants noted that many people affected by HIV and TB lived in shacks or other small houses, with handfuls of people living in enclosed spaces, often with only one door and perhaps no windows. As Paul Kasonkomana from Zambia said, "most of the houses that I go to, especially in rural areas or [informal

settlements], have no windows and one door and sometimes up to 12 people staying in there. And you want me to talk to them about infection control?"

Kasonkomana also noted that focusing on infection control does not address larger socio-economic concerns such as gender inequality, inadequate nutrition, limited access to transport, and inflexible employment opportunities. All of these severely affect both people's vulnerability to HIV and TB, as well as ability to institute effective prevention techniques and access essential care. Additionally, infection control within healthcare settings, such as clinics, remains low in all represented countries, with triaging often only occurring after TB diagnosis; while over-crowded facilities; lack of information about proper cough etiquette and hygiene; and poor to average ventilation are common in most countries.

Inadequate understanding of science and policy by health care workers, the general public, government, and civil society

In communities across Southern Africa, there remains a low level of understanding of the science, policies, and politics behind public health, leading to limited policy implementation; patients don't recognise the importance of prevention technologies, continued testing, and drug adherence. Health care workers don't fully understand the benefits of technologies and policies or how they should be implemented. As Chirwah Mahloko from Botswana said "you can't demand something that you don't understand." According to the pre-workshop surveys, only Zambia and Botswana had facilitated mobilisation for the Three I's for HIV/TB, and even these activities left much to be desired. While representatives claimed that surveillance and treatment of health care workers is adequate, stock outs of N-95 masks continue to put HCWs at risk of infection.

Unacceptably low political will noted by all participants

Despite signing numerous declarations regarding the right to health, few governments provide leadership, capacity, or financing to ensure that health care is accessible to the majority of the population, with essential scale-up in services and implementation of WHO guidelines greatly lacking. While all five represented countries had national-level coordinating bodies to implement the Three I's for HIV/TB, none but Zambia had district/facility implementing bodies.

Lack of accurate data and little monitoring and evaluation (M&E)

All workshop participants noted the dire lack of data within southern Africa. "It is often the countries with the highest HIV and TB epidemics that have the worst data," said the WHO's Smyth, "so the figures currently used for the region may actually grossly under-represent the true burden of disease and lack of services." Monitoring and evaluation of the Three I's for HIV/TB is especially wanting, with only two of the five countries represented at the meeting having a formal structure in this regard.

Disconnect between HIV and TB services

Despite continual and persistent recommendations from the WHO and others that HIV and TB services work together, in reality very few southern African countries have combined the two, with patients being shuffled from one clinic and laboratory to another rather than being able to access multiple services at a one-stop-shop.

Based on the pre-workshop survey, only Swaziland, Mozambique and Zambia had national committees focused on HIV and TB coordination. In the absence of integration, more time, money, and effort is demanded of the patient, effectively dissuading them from testing, receiving adequate treatment, and pursuing follow-up care. Screening for TB among people living with HIV remains

unacceptably low in all represented countries, with contact tracing also poor in all countries but Botswana.

Limited relationship between government and civil society

While participants noted that represented countries had some level of interaction between civil society and government, many felt that this was often tokenism, with civil society partners being handpicked and not being included in more technical work such as strategic planning.

Botswana's Kelemi said that she often wondered if civil society was "invited simply to say that they were included, but without our voices or concerns and inputs really being considered." In the pre-workshop survey, while representatives from each country noted that there was formal engagement with government and civil society, strategic planning was often restricted to the Ministry of Health, and several countries were sceptical about which organisations were chosen to be included in such activities. The Swaziland survey specifically noted "marginalisation of civil society in [Ministry of Health] meetings."

Country profiles

Five southern African countries were represented at the December workshop, each with varying degrees of HIV and TB disease burden and response. Below are basic profiles of represented countries based on available statistics and pre-workshop surveys conducted by civil society representatives.

Botswana

As of 2009, 300,000 adults were living with HIV, or one quarter of the population aged 15 and above. The country has the second highest adult prevalence in the world, second only to Swaziland. Antenatal rates are especially worrisome, with approximately 33% of pregnant women presenting to antenatal care testing HIV-positive in surveillance surveys.

TB heavily affects the general population and is particularly prominent among those living with HIV, with upwards of 66% of TB patients being co-infected. There were 7,966 new TB cases in 2009, with treatment success between 54-65% among new patients in 2008. MDR-TB rates are high in the country, with 3.4% of new patients and 13% of re-infected patients presenting with MDR-TB as of 2008.

Despite these statistics, the country is often seen as one of the leaders in the region in the fight against HIV and TB. IPT has been available in Botswana since 2004, and is included in a comprehensive HIV package of care; in 2009, over 11,000 people living with HIV received the prophylaxis. Recently, Botswana has conducted a review of the IPT programme, and is now re-piloting the service within the HIV programme (rather than through the national TB programme). Botswana reports that it has achieved universal access to ART, with over 80% of those in need receiving treatment. The country's PMTCT programme reaches 95% of those in need. TB funding has steadily increased since 2006, but a gap remains between budget and monies available.

Lesotho

Lesotho has the third highest general prevalence of HIV in the world: nearly one in four people is infected, bringing the total to around 300,000 people. While PMTCT efforts have increased, still just over 60% of HIV positive pregnant women are able to access adequate services. Free treatment through government services has only been available since 2004. The programme has been seriously hindered by massive shortages in trained HCWs, and as of 2009, 62,000 people were accessing treatment, or 48% of those in need. General HIV knowledge as well as testing remains low, with

only one in five males aged 15-24 being able to identify ways to prevent sexual transmission of the virus.

Poor health financing and limited political will has hindered the HIV response, with the country offering little in the way of accurate data. In 2009, 11,545 people were newly infected with TB. In 2008, 0.9% of newly infected patients presented with MDR-TB, with 5.7% of those re-infected having MDR. Over 60% of both newly infected and re-infected patients successfully completed treatment in 2008. As of 2009, 77% of TB patients were also infected with HIV. Access to testing facilities is abysmally low, with 0.9 smear laboratories per 100,000 people in 2009. Since 2006, available monies for TB efforts have fallen far below what the budget requires.

Zambia

As of 2010, one Zambian adult in seven was living with HIV, with women aged 15-24 sporting rates four times that of their male counterparts. Countrywide, 120,000 children are infected. As a result of the high burden of disease, the country's life expectancy now lies at a staggeringly low 39 years. While UNAIDS considered the HIV epidemic to have "stabilised" as of 2008, condom use, knowledge of status, and HIV/AIDS awareness remains low.

By 2009, 69% of HIV-positive pregnant women were receiving PMTCT, with 64% of PLHIV needing treatment gaining access. Comprehensive and widespread testing, treatment and care are hindered by a severely constrained public sector with far too few doctors. In 2009, there were over 43,000 new cases of TB in the country, with 67% of TB patients also having HIV. In 2008, 1.8% of new TB cases were MDR-TB, with 2.3% of relapse cases being MDR. The country touts over 80% treatment success rate among both re-infected and newly infected individuals. As a result of corruption and a global funding crisis, the country faces a huge funding gap in both its HIV and TB efforts.

Swaziland

Swaziland is one of the most heavily impacted countries in the region, with the highest HIV prevalence in the world, resulting in one in four adults living with HIV and 15% of the population being orphans and vulnerable children. The country has a life expectancy of 32 years, the world's lowest, with 39% of the total population under the age of 14. In part because of widespread stigma and discrimination, and despite a substantial increase in testing facilities, as of 2010, only 16% of adults knew their HIV status. Condom use remains low.

As of 2009, nearly 60% of those in need for ART were receiving it. PMTCT rates are promising, with 88% of pregnant women testing positive receiving ARVs. As is true throughout the region, too few doctors and nurses is hindering the HIV and TB response. 84% of TB patients are HIV-positive, one of the highest co-infection rates in the world. Only 26% of co-infected persons were receiving ART as of 2009. Just over 2,000 HIV positive people received IPT in the same year. As of 2009, there were 9,558 new TB cases, with 63-68% being properly treated. In 2008, 0.9% of new TB patients had MDR-TB, with 9.1% of re-infected patients presenting with MDR-TB. While available funding to battle TB has mostly risen since 2006, there is still a large gap between availability and need.

Mozambique

While PMTCT and condom promotion is underway, HIV testing and counselling is extremely limited. As of 2009, just over 170,000 people eligible received ART, substantially more women than men. Over 68,000 HIV-positive pregnant women received PMTCT services in 2009. 66% of TB patients also tested HIV positive in 2009, with only 10% of them receiving comprehensive treatment. In 2009, 41,899 new cases of TB were diagnosed, with upwards of 84% being properly treated. In 2008, 3.5% of new cases were MDR-TB,

with 11% of re-infected individuals having MDR. There are limited testing facilities within Mozambique, with just 2.8 smear laboratories per 100,000 people in 2010. Available monies for 2011 fall far below what the national TB budget calls for, with available monies decreasing steadily since 2008.

So, what can we do? What is needed to effectively move forward

Advocacy, communication, and social mobilisation (ACSM)

Group work focused on creating communication and advocacy strategies to address specific scenarios given to participants. A theme that ran throughout the workshop was that of a patient-centred approach, acknowledging that advocacy strategies discussed would only be effective if impacted communities were educated and intricately involved. As one participant noted, “you will only be outraged if you know what’s supposed to be given to you.” A rights-based approach to messaging was championed, with communication strategies focusing on empowering patients in order to create service demand and positive messaging.

In order for efforts to be effective, participants encouraged greater market research so that messages could be tailored to specific communities. Duplication of messaging must also be avoided so as to not create fatigue amongst target populations. Both traditional and innovative forms of messaging were suggested, including posters; billboards and advertisements; flyers; so-called “edutainment” (the use of community theatre, especially in congregate settings such as prisons, etc.); booklets; SMSes; radio jingles; social media such as Facebook and Twitter; and so-called “media champions” including radio DJs who regularly include HIV and TB messaging in their shows.

Suggested “sticky messages” included:

- With regards to symptom-based screening for IPT: “Just four questions can save your life”
- “Demand to stay alive”
- “Be a victor not a victim”

Proposed Toolkit content

Based on workshop discussions, the Three I’s for HIV/TB advocacy toolkit is currently being written, and is expected to include the following:

- HIV and TB FAQs, including regional statistics;
- A simple translation of the Three I’s for HIV/TB that can be understood by a variety of people, from government officials to HCWs to patients affected by HIV and TB;
- Training manual on the Three I’s for HIV/TB for HCWs;
- Literature review of research concerning HIV and TB prevention and treatment, including costing analysis;
- A series of posters concerning the Three I’s for HIV/TB specifically focusing on screening; infection control (including check list and resources for external support regarding socio-economic factors); intensified case findings (including algorithm); implementing the strategy within congregate settings; IPT (including guide to symptoms-based screening, focus on TB and HIV integration, and resources for adherence support); and best practices from across the region;
- Patient’s rights booklet;
- Training manual for activists and training of trainers; and
- Key advocacy, education, and communication strategies for all stakeholders, including suggested messages; outline of drama or

Q & A with facilitators guide; support for M & E efforts; and a strong focus on networking and fundraising tactics.

The toolkit aims to:

- Encourage greater transformation from policy into practice, especially at the service-delivery level;
- Foster the creation of patient-centred demand through increased access to information and a rights-based approach;
- Encourage professional buy-in by HCWs and policy makers to ensure that the Three I’s for HIV/TB are properly implemented; and
- Place science within a realistic, social context.

The toolkit will be targeted to reach a variety of stakeholders, including health care workers, patients, the general public, use in congregate settings (such as prisons, refugee camps, schools), and civil society. Piloting has recently begun, with civil society organisations and government currently assessing the work.

Please note that this content is subject to change as the tool kit is still being finalised.

Key lessons learned

In addition to creating content for the toolkit, several other themes and lessons emerged from the week-long workshop, pointing to other work to be done.

How communication amongst civil society organisations can increase so as to facilitate knowledge-sharing and reduce duplication

Throughout the workshop, participants continually noted that their experiences heavily mirrored those of their colleagues in other countries, and that learning about best and worst practices helped them to reflect on their own work. Discussing government-targeted advocacy as well as funding opportunities and strategies was considered extremely helpful. Such reflections point to the need for more regional workshops, in which representatives from different countries can share experiences in order to strengthen their own work as well as ensure that this work aligns with a regional strategy.

The need for continued training and greater treatment literacy among civil society organisations

The December workshop focused on ensuring that WHO guidelines could be easily understood by a variety of people in order for advocacy to effectively take place. Notably, many civil society participants were still unclear on policy guidelines and the science behind such policies. Thus it cannot be assumed that those working in HIV and TB necessarily have access to essential knowledge, and continued training is necessary to ensure that civil society organisations are well informed, which will in turn spur effective advocacy approaches. In fact, if civil society wants to be at the table where policy is being made, community representatives have a responsibility to become better versed in treatment science to make certain that their community is well-served.

The need for increased communication between the WHO and civil society

The challenges are substantial confronting civil society in its efforts to become active partners in advocacy, treatment education and service delivery — and a recurrent issue participants raised at the meeting was how much and what sort of help can WHO offer the community?

The workshop itself was clearly a positive and productive step. Both WHO and civil society participants noted that workshops such

as these could help to facilitate a better working relationship. There is a clear and ongoing need for communication and cooperation between WHO and the community. In order to avoid a 'top down approach' and increase the community's interest in and the ability to advocate for the implementation of national and international guidelines, there needs to be regular input from the community. Without such involvement, unrealistic policy recommendations for resource-limited settings are easily fostered, making their implementation difficult and potentially diverting attention away from other essential programmes.

WHO generally make recommendations focused on public health interventions including medical practice. Guidelines usually do not address structural concerns such as poverty, housing, transport, and limited health care facilities.

As previously mentioned, suggesting that households open windows, in settings where there are security issues, and when there is widespread overcrowding and access to limited housing opportunities does not take into account both communities' reality, as well as communities' needs. In addition to giving potentially unrealistic guidance in some circumstances, there is a limit to how much pressure WHO guidelines can put on government to fix fundamental human rights and public health issues that facilitate the spread of HIV and TB. Participants noted that such a limited approach that fails to address the structural and social co-factors that fuel the HIV/TB epidemic may in turn only produce limited results.

Of course, these structural concerns and social co-factors are issues that civil society organisations must tackle within their own respective countries.

As noted earlier, civil society felt that WHO's country and regional offices could do more to help broker better relationships between the community and their local government's health officers. Finally, civil society participants called on the WHO to offer more support in their programmes, specifically by collaborating on advocacy activities to help to ensure a positive response by government.

WHO's Dr. Reuben Granich also encouraged participants to remember that the WHO was there as just one part of the public health response. "Guidelines should be seen as one part of necessary advocacy and programming to increase access to care," he said. The toolkit is also meant to address in part these differences between policy and practice by aiding communities in considering how the Three I's for HIV/TB can be tailored to suit different communities' realities and needs.

At the same time, there could be other concrete steps that WHO might take to improve community engagement and representation at the national and regional level. In fact, at the earlier meeting between the community and WHO's STOP TB Department, WHO's STOP TB Department committed to the following action points:

Action points:

- **WHO to explore including a specific activity item on enhancing civil society organisation involvement in the terms of reference of its staff working on TB at all levels.**
- **WHO to promote and conduct context-specific international, regional and national meetings that convene higher level decision makers within ministries of health (e.g. permanent secretaries or directors), national TB programme managers, civil society organisations and WHO staff to develop global, regional or country-specific roadmaps to engage civil society organisations in TB prevention, care and control efforts.**

- **WHO to continue including civil society organisations in its global and regional TB policy and programme guidance development processes and decision-making bodies.**
- **WHO to encourage the participation of civil society organizations in national TB control programme reviews.**

The WHO-ARASA work shop represents a part of WHO's commitment to achieving the above commitments to its stakeholders.

ARASA's Akugizibwe also stressed the importance of civil society taking the initiative, looking to their own needs, knowledge, and resources in order to implement community-specific programmes rather than waiting for government or organisations like the WHO to intervene.

While advocating for governments to fulfil their commitments and guideline development process to be more inclusive of communities is important, "It is impossible to escape the fact that the resources at the disposal of health systems are dwarfed by the needs presented by this vast co-epidemic," she said. "Civil society must therefore take matters into their own hands when possible, and develop creative ways to fight the epidemics with or without help and support from government and international partners. This is not to say that civil society efforts should replace governments', but rather should complement them and should be done in conjunction with push-and-pull advocacy, with organisations considering where their resources are most effective to fill the gaps, and where external support is needed."

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[1] The countries represented in this report are Mozambique, Zambia, Botswana, Lesotho, and Swaziland. While no South African representative attended the meeting, the country will be included in the final tool kit.

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about HATiP

A regular electronic newsletter for health care workers and community-based organisations on HIV treatment in resource-limited settings.

Its publication is supported by the UK government's Department for International Development (DfID), the Diana, Princess of Wales Memorial Fund and the Stop TB Department of the World Health Organization.

The newsletter is edited by Theo Smart (Cape Town) and Keith Alcorn, NAM's Senior Editor (London).

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