Time for Action on TB Communication
A briefing for policy-makers, programmers and health communicators on contemporary communication opportunities and challenges
**Acknowledgements**

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### Abbreviations and acronyms

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<th>Acronym</th>
<th>Description</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immuno-Deficiency Syndrome</td>
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<tr>
<td>CBO</td>
<td>Community-based organisation</td>
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<td>CCM</td>
<td>Country Coordinating Mechanism</td>
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<td>CDC</td>
<td>Centre for Disease Control and Prevention</td>
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<td>CIDA</td>
<td>Canadian International Development Agency</td>
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<td>COMBI</td>
<td>Communication for Behavioural Impact</td>
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<td>CSO</td>
<td>Civil society organisation</td>
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<td>DFID</td>
<td>UK Department for International Development</td>
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<td>DOTS</td>
<td>Directly observed treatment, short-course</td>
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<td>GFATM</td>
<td>The Global Fund to Fight AIDS, Tuberculosis and Malaria</td>
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<td>HBC</td>
<td>High-burden country</td>
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<td>HIV</td>
<td>Human Immuno-Deficiency Virus</td>
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<td>IEC</td>
<td>Information, Education and Communication</td>
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<td>IUATLD</td>
<td>International Union against Tuberculosis and Lung Disease</td>
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<td>JHU/CCP</td>
<td>Johns Hopkins University Center for Communication Programs</td>
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<td>KNCV</td>
<td>Royal Netherlands Tuberculosis Association</td>
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<td>MDG</td>
<td>Millennium Development Goals</td>
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<td>MDR-TB</td>
<td>Multi-drug resistant tuberculosis</td>
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<tr>
<td>NGO</td>
<td>Non-governmental organisation</td>
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<td>NTP</td>
<td>National Tuberculosis Control Programme</td>
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<td>PLWHA</td>
<td>People living with HIV/AIDS</td>
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<td>PPM-DOTS</td>
<td>Public-Private Mix for directly observed treatment, short-course</td>
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<td>SADC</td>
<td>Southern African Development Community</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>USAID</td>
<td>US Agency for International Development</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Executive summary

This briefing outlines why communication should be placed centrally on the tuberculosis (TB) agenda. Many logistical and medical components of the global response to TB are relatively robust. The communication part is not. Cure rates are high, but the numbers of people with TB who require medical help are low. Better communication, which includes advocacy, social mobilisation and programme communication, would provide much of the solution to this and a number of other problems within today’s fight against TB.

A cure for TB has been available for nearly 50 years. Yet DOTS (directly observed treatment, short-course) – the strategy recommended by the World Health Organization (WHO) for fighting the disease, and which is used internationally – did for a long time not carry a communication component. A communication component is only now, in October 2005, being incorporated, and it is still unclear how it will be embraced at the country level.

Challenges

We outline below a number of communication challenges relating to TB:

- Increasing case detection through public engagement, moving beyond merely awareness-raising.
- Closing the time gap between the onset of TB symptoms and the seeking of treatment.
- Involving national and international partners and linking with broader health and development campaigns and movements.
- Supporting the involvement of activists and TB patients in defining strategies for controlling TB and reducing stigma associated with the disease.
- Supporting civil society in monitoring government responses to TB.
- Embracing large numbers of private healthcare providers within a comprehensive TB response.
- Addressing the issue of TB/HIV co-infection, and capitalising on successful HIV/AIDS communication interventions.
- Mobilisation and advocacy for the strengthening of health systems, since without stronger health infrastructures most public health goals, including TB elimination, are unlikely to be achieved.

Addressing these communication challenges will significantly enhance the response to TB, ensuring greater public mobilisation, political commitment, and real improvements in case detection and cure.
Introduction

TB – a background

Between 1994 and 2003, more than 17 million TB patients across the world were treated under DOTS, the WHO-recommended international public health strategy for TB control. This is a remarkable achievement by most standards. However, the problem of TB is a long way from being under control.

An estimated one-third of the world’s population is infected with the *Mycobacterium* bacillus that causes TB. Each year, nearly 9 million people develop active tuberculosis. Close to 2 million people die from TB annually, even though an effective cure has been available for nearly 50 years. Today, despite the expenditure of vast sums of money, less than 50 per cent of the estimated cases of new infections each year are detected and treated.

Our failure to respond to TB is largely a communication failure. People suffering from TB symptoms often think they just have a cough rather than TB. Likewise, those affected, and their care-givers, often do not know where to find help. National political and health programming leaders continue to devote insufficient attention and resources to tackling this curable illness. The media and civil society largely leave the problem of TB to the medical community, and take no action to mobilise funds or force TB onto the public agenda. An increasingly networked, informed and globalised civil society has led to international social movements on poverty, gender and specific health issues such as HIV/AIDS. Yet few campaigners on these issues make the connection with TB, meaning that the fight against the disease fails to benefit from broader and more creative public engagement.

Ten consecutive years of robust data (1994-2003) on the TB epidemic are now available to assess trends and progress in global TB control. Close to 80 per cent of the global TB burden is carried by 22 developing countries, mostly in Asia and Africa. Just five countries – India, China, Indonesia, Nigeria and Bangladesh – account for 50 per cent of the global burden.

The expansion of DOTS programmes to achieve 100 per cent geographical coverage within countries (which is crudely equivalent to population coverage) has been central to TB control efforts. Two ‘process’ or implementation targets for case-detection and cure rates have driven the control agenda ever since the disease was declared a global emergency by the World Health Assembly in 1993. These are:

- Detecting, by 2005, at least 70 per cent of the estimated number of infectious (smear-positive) cases of pulmonary TB
- Successfully treating, also by 2005, 85 per cent of those detected.

Three Millennium Development Goal (MDG) ‘impact’ targets, to be achieved by 2015, are of direct relevance:

- To have halted and begun to reverse the incidence of TB
- To reduce TB prevalence rates by 50 per cent in relation to the year 1990
- To reduce TB death rates by 50 per cent in relation to the year 1990.

If the prevalence rate is to be halved by 2015, WHO’s targets for global detection and treatment success must be met; yet according to the 2005 WHO Global TB Control Report (based on 2003 data), only 45 per cent of TB cases are actually detected, and 82 per cent of these are cured. Beginning to reverse the incidence rate by 2015 requires reducing it by at least 2 per cent annually (currently it is rising by 1 per cent annually). To halve the death rate, incidence must decrease even more steeply – by at least 5-6 per cent annually. The challenge is enormous, and can only be met through innovative and comprehensive communication strategies.

Successful advocacy to date

WHO and the Stop TB Partnership – a coalition of 400 organisations committed to the elimination of TB as a public health problem – have helped keep TB on the agenda of international organisations and donor agencies. This advocacy has often been crucial: indeed, TB was not even explicitly mentioned in the MDGs when they were first published.

The last ten years have seen most TB advocacy efforts, and associated activities in the media, directed at building high-level political commitment in the international development arena and mobilising resources for global TB control. These efforts have been largely successful.

TB was deftly placed on the global health agenda in part through strategic leverage of the media during TB outbreaks in New York and areas of London in the early 1990s.

In 2000, strategic advocacy with the media in the run-up to a landmark conference of health and finance ministers from 20 high-burden countries (HBCs) in Amsterdam, followed by the G8 Summit in Okinawa the same year, which made specific references to TB, firmly established TB as a global public health threat deserving high-level attention and large-scale financing. The creation of The Global Fund to Fight AIDS, TB and Malaria (GFATM) provided further impetus.

A simple but rather crude indicator used to measure political commitment is the level of funding committed by international agencies and national governments for TB control. According to the 2005 WHO Global TB Control Report, there have been rapid increases in this funding, especially in the past two years. The majority of spending in HBCs comes from national government budgets.

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In 2005, of the total estimated costs in the HBCs, contributions from national governments (including loans) are expected to be 62 per cent, GFATM will contribute 15 per cent, and contributions from all other grants will total 7 per cent, leaving a gap of approximately 16 per cent. While this gap is significant and efforts to cover the shortfall must continue, it no longer needs to dominate the TB communication agenda.

Towards a shared understanding of ‘communication’

An important first step towards developing strong communication strategies is the need for a shared understanding of some key terms used in the context of communication. While it is difficult to arrive at precise definitions of terms such as communication, advocacy and social mobilisation, some broad descriptions are offered here, which are useful for the purposes of understanding, structuring and categorising communication activities in relation to TB.

The word communication is used here as the overarching term for advocacy, social mobilisation and programme communication. Following on from this, the term health communicator refers to individuals who work in advocacy, mobilisation or some aspect of programme communication.

In the global context, advocacy for TB is to be understood as a broad set of co-ordinated interventions, directed at placing TB high on the political and development agenda, so as to secure international and national commitment to controlling/eliminating the disease and to mobilise the requisite resources. In country contexts, advocacy efforts broadly seek to ensure that national governments remain strongly committed to implementing TB control/elimination policies.

In the national and sub-national contexts, social mobilisation is a process of generating public will, by actively securing broad consensus and social commitment among all stakeholders for the elimination of TB, as a public good. Community mobilisation is a grassroots-level process in the context of wider social mobilisation.

Within countries, and in the context of TB control, programme communication primarily seeks to inform and create awareness among the general public about TB (e.g. its symptoms and the fact that it is curable) and the services offered by the health system (for diagnosis and treatment), and to encourage people to seek treatment if they have the symptoms. Additionally, specific and targeted messaging may be deployed, to facilitate behaviour change or meet a particular behavioural goal.

The lines between advocacy, programme communication and social mobilisation, especially in national/sub-national contexts, are often blurred. Interventions within a particular category may well influence or facilitate processes in the other categories.
**Challenges**

**Fund disbursal**

Spending by national TB programmes still lags far behind available funding. Data from 15 HBCs for the year 2003 showed that compared to a total budget of $273 million, and an actual availability of $239 million, only $193 million was spent by national TB programmes. While health ministers from the worst affected countries commit to the TB effort, the health services for which they are accountable seem to move more slowly. Furthermore, even though there is now a large increase of funds from GFATM, between the approval of proposals and the first disbursal there is an unacceptable delay, of between five and 23 months (median = 11 months). Advocacy efforts must now be specifically directed at rapid, effective spending by national TB programmes and accelerated disbursals from GFATM.

**Social mobilisation**

In recent years, many senior TB programme managers and partners, including national TB programme managers, have agreed that securing funding and building international commitment are no longer top priorities, because of the success of past advocacy efforts. Instead, what is critical now is social mobilisation directed at building widespread political and social commitment to TB control programmes. Yet TB remains outside of popular development discourse. Unlike HIV/AIDS, gender and other big issues, it is not one that the wider public engages with. Communication efforts are needed to mobilise the public into making policy and programming demands and holding decision-makers to account. Only a clear communication strategy, which engages civil society, can bring about sufficient public awareness and ownership to ensure this accountability.

Much of the public and political apathy is historically attributable to an approach that can be characterised as technical and purely medical. To put it simply, TB has long been a problem left to the clinical establishment. Largely because there is a cure, administered within the healthcare setting and benefiting millions, TB has not been taken up as a popular cause.
Detection and active outreach

Less than half of all TB cases are currently detected, and this presents a major challenge for communication. Even among the cases that are detected and treated, there is often a very long delay between the onset of symptoms and diagnosis.

Poverty and TB

In the past, TB – or ‘consumption’ as it was called then – was a disease of the rich and poor alike. Today, it is principally the poorest and most marginalised in society who contract and die of this ancient, yet curable, disease. There is a direct link between poverty and TB. The poor are likely to live in crowded situations with poor sanitation, heightening the risk of contracting TB. They are also less likely to be able to access healthcare, vaccination and DOTS. Treatment of TB often requires numerous visits to a number of different healthcare providers. This lengthy pathway to treatment is far more onerous for the poor, who may lack transport and may also find it difficult to get away from work for the day. Loss of income, along with the direct and indirect costs of seeking treatment, further inhibits prompt seeking of medical help.

Lack of awareness about TB is also greater among poorer populations. The main symptom – a persistent cough of two weeks or more – does not trigger a prompt health-seeking response, as poor people often have episodes of a persistent cough due to other chronic health conditions. Only when patients start to become seriously ill do they start looking for diagnosis and treatment. More often than not, the poor ‘shop around’ for services from a variety of local health service providers, and only end up seeking qualified help from the public health system when their health deteriorates significantly.

More than a dozen studies have shown that the delay between the onset of symptoms and first diagnosis can be anywhere between two and six months. Given the highly infectious and contagious nature of pulmonary TB, and the fact that each patient can infect another 10 to 15 persons each year, communication strategies to address this issue and facilitate faster detection and diagnosis are urgently needed. Even if case-detection rates are improved, as long as delays between onset of symptoms and diagnosis are not addressed, the transmission of TB will not be stopped.

Once TB patients enter the DOTS system of services, there is a very high chance of being cured. However, the consistently low case-detection rates strongly suggest there is a critical element missing in the DOTS strategy: the communication that draws patients to health facilities. The DOTS strategy is based on ‘passive’ case-finding. People in need are expected to simply come for treatment, or to be referred by other parts of the health system. There is little active outreach to bring them in. The fact that the five principal components of the DOTS strategy (political commitment, diagnosis through smear microscopy, assured supply of quality drugs, directly observed treatment, and recording/reporting treatment outcomes for all patients) do not include a specific communication element is a key cause of this problem.

Nhlema, B et al., 2003, A Systematic Analysis of TB and Poverty
<table>
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<th>Stigma</th>
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<td>TB is often intensely stigmatised in the developing world. Studies show that in many cultures, TB is associated with pollution or weakness, or attributed to a curse. People can be reluctant to disclose their status to even the closest of friends or relatives. Those living with TB often isolate themselves, viewing themselves as disease vectors or contagions. Eating together or sharing close quarters is often made uncomfortable or impossible through self-imposed or enforced isolation. In some South African settings, TB sufferers are considered witches or sorcerers. A study in Mexico City showed that 52 per cent of patients discharged from hospital after TB treatment were not allowed to go home. Many other anthropological studies point to similar trends.</td>
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| Peers who are HIV-positive often stigmatise TB patients as they fear infection, knowing they are more vulnerable. This can also jeopardise treatment, as many health workers and nurses in hospital might be HIV-positive and inadvertently stigmatise TB patients. |

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**TB, HIV/AIDS and multi-drug resistant TB**

TB can affect any part of the body. But it is pulmonary TB, or TB of the lungs, that is particularly infectious because it is transmitted through the air that each of us breathes. Each person afflicted with pulmonary TB can infect between 10 and 15 persons each year. Bring HIV/AIDS into the equation, and the picture becomes even grimmer, and one that is currently being experienced, particularly in Africa.

Approximately 10 per cent of people with latent TB infection who are also HIV-negative will develop active TB in the course of their lifetime; in comparison, 10 per cent of people with latent TB infection and HIV/AIDS will develop the active TB disease each year. HIV/AIDS is the greatest risk factor for developing TB in those with latent infection. Conversely, TB is among the biggest causes of morbidity and mortality among people living with HIV/AIDS. With an estimated 40 million people already infected with HIV/AIDS, and an estimated 2 billion carrying latent TB infection, the global TB situation is a ticking time-bomb.

To treat and fully cure a person with TB, a life-saving course of six to eight months’ worth of anti-TB drugs costs as little as $10-12 in most parts of the developing world. Anti-TB drugs can cure infectious TB even among people living with HIV/AIDS. However, poor diagnosis and faulty or interrupted treatment often lead to multi-drug resistant TB (MDR-TB), which is even more dangerous, and far more difficult to treat. Second-line drugs used for treating MDR-TB are more toxic and often have severe side effects. The cost of the treatment can be as high as $12,000 per patient, which is out of reach for most people, and can place a massive financial burden even on national governments.

Those infected with both TB and HIV/AIDS can benefit from TB treatment. This calls for close co-ordination of activities between national TB and HIV/AIDS programmes. Setting up collaborative mechanisms, and undertaking intensive case-finding and testing for TB among people living with HIV/AIDS, and vice versa, followed by appropriate counselling and provision of treatment and care, are urgently needed, along with the associated communications tools and support.

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9 www.cdc.gov/nchstp/tb/pubs/Behavioral_Forum_Proceedings/Section4_App/AppC/AppC_V_Community.htm
10 Helman, CG, 1997, Culture, Health and Illness, Butterworth – Heinemann
12 Helman, CG, 1997, Culture, Health and Illness, Butterworth – Heinemann
13 Panos/UNICEF, 2002, A five-country study of stigma in the context of healthcare settings
In the North, the stigma associated with TB has its roots in the deadly epidemics of the mid-19th century, when millions of Europeans and North Americans were killed by the then incurable disease. Stigma began with the isolating of patients in sanitaria, at that time perhaps the only way of containing the transmission of the disease. Newer forms of stigma and discrimination, around TB associated with HIV/AIDS and TB/HIV co-infection, may also be emerging, with one feeding off the other.

Even though TB has been high on the scientific agenda in the past, with four Nobel prizes awarded between 1900 and 1950 to scientists who had directly worked on TB-related research, few well-known figures championed the cause of TB sufferers politically. More recently, however, Nobel laureates Archbishop Desmond Tutu and Nelson Mandela, both of whom survived TB, have lent their voices to the campaign to put TB on the global agenda. There is no doubt that the outspoken support of such highly respected figures can also help reduce stigma.
Communications strategies and the fight against TB

The need for communication capacity

TB programme managers have to deal with DOTS, health systems, MDR-TB, financing, TB/HIV co-infection and a number of other complicated issues. They have little time to think about communication. At the same time, the structures they work within, particularly in high-burden countries, are acutely under-resourced. There are insufficient staff, often under-paid, working with poor facilities and often with low morale. This is not an environment where innovative communication approaches are likely to flourish. Added to this, there are few staff with strong communications backgrounds. Those that do have the requisite skills are more likely to work outside of the health sector where there are better rewards.

TB programme managers need to be able to turn to strong communications professionals able to offer advice and strategic input. Where communications staff do exist, they could often benefit from further training, and where they do not exist, they need to be urgently recruited.

Consolidating communications approaches

There are currently a wide variety of communication approaches that have been used in the response to TB. These include the Communication for Behavioural Impact (COMBI) approach developed by WHO, and the P Process, which was developed by Johns Hopkins University/Center for Communication Programs for shaping up interventions. A wide variety of social marketing and Information, Education and Communication (IEC) approaches have been used. The Cough to Cure Pathway, developed by Silvio Waisbord, is another useful tool. Other relevant approaches include those that focus on creating enabling communication environments or that encourage community action for social change (the Communication for Social Change approach). Some approaches focus on long-term sustainable change, others aim for high impact across large audiences in the short term. While some approaches focus on the politics of communication, others aim to raise awareness on relatively simple issues. Each has its own value.

For an overview of these approaches, refer to the Communication Plan for Country Level Advocacy, Communication and Social Mobilisation at the Stop TB Partnership website www.stoptb.org
All of these approaches offer a bewildering choice to busy TB programme managers at the country level. Those without training will find it hard to select the most useful or relevant approach to different settings. There is a real need for different TB communication approaches to be collated and consolidated so as to increase their practical application to the actual problems that TB poses. A single, simplified toolkit should be developed, which takes the best from each communication approach and confronts every level of the issue – from overall communication environments to specific interactions in healthcare settings.

**Public awareness and social mobilisation**

The very first step in strengthening political and social commitment to fighting TB, especially at national and sub-national levels, is to build a critical mass of people who understand TB as a development issue. Too often within public discourse, TB is seen as a grim problem, largely to be avoided, and of little interest to the general population. Efforts to draw out the relationships between this public health issue and other elements of social and economic life can enhance the relevance and immediacy of the problem. Asking celebrities touched by TB to tell their stories can help raise awareness about TB among the general public. Work on HIV/AIDS and other development issues shows the importance of moving beyond merely building awareness to also promoting active engagement and local ownership of the TB issue and solutions. Similarly, other health communication lessons around the quality of public discourse, the importance of a cohesive social response and the importance of mobilising from existing political platforms, should be explored for their pertinence to the issue of TB.

Few countries have conducted surveys to assess awareness and knowledge levels about TB among their populations. The little that is known, either through surveys or anecdotal evidence, points to a fairly low level of public awareness – either about TB as a public health issue, or about its symptoms and the diagnostic/treatment services available.

Establishing existing baselines, and setting specific and measurable goals for achieving a critical level of awareness about TB among the general population, will go a long way towards developing appropriate communication interventions.

Indicators on awareness should be included in the National Tuberculosis Control Programme (NTP) reporting formats to measure progress, from district level through to the national level, and in the annual country reports submitted to WHO.

The media will play a key role here, going beyond newsroom reporting that draws on dry statistics and official press releases. Initiatives are needed that embed TB within other spheres of daily life to help catalyse public interest in the issue and promote discussion. From investigative documentaries, through to TV soaps and chat shows, a range of media formats can help place TB meaningfully into the contexts of popular discourse.

TB communication must go beyond the usual flurry of media and communication activities around World TB Day – the only day of the year when there is any perceptible buzz around TB. Commemoration of World TB Day, at least in the high-burden countries, is still largely led by the National TB Control Programme. However, national Stop TB campaigns with clear visions and coherent goals and objectives, which include a strong role for civil society and are supported by a vibrant and independent media, will go a long way towards effectively addressing some of the key challenges in TB communication.
International media awards and fellowships could be developed that help publicise developments in TB treatment, particularly in relation to the efficacy of new public health approaches to TB, interactions between HIV/AIDS and TB, emerging MDR-TB epidemics and associated dangers. These international media interventions should relate to a clear framework of current TB goals, targets and associated timeframes. Beyond the media, a range of institutions could be mobilised to embrace TB within their activities and agendas. Materials and tools could be adapted to help various groups, from sports clubs to faith organisations and youth groups, to do this.

**Involving networks of affected people**

Increasing effort has been devoted to building TB patient-activist groups and establishing linkages with people living with HIV/AIDS (PLWHA) networks. Greater involvement of TB patients in all decision-making processes is essential to ensure better-tailored and more relevant policies. Spaces need to be made for patient-activist groups to participate and contribute meaningfully to the global TB control agenda, because at present they do not exist and tokenism abounds. When people affected by TB can participate in monitoring of government policies, then a strong catalyst for change emerges. An example of this kind of monitoring can be seen in the work of Public Health Watch in a number of countries.

It is also useful to question what kinds of TB patient networks can be formed and sustained. Given the stigma that is associated with TB (and now its linkages with HIV/AIDS), and the fact that TB is curable, large-scale TB patient networks may be difficult to build. Without a more carefully thought-out process regarding their involvement, TB patients would want simply to get cured and move on, rather than remain linked to something that has strong stigma associated with it.

The scenario is different for lifelong conditions, as for those affected by HIV/AIDS or TB/HIV co-infection, or MDR-TB for that matter. The situation unfolding in Africa and Eastern Europe demands the creation of networks and linkages with HIV/AIDS and MDR-TB groups of patients. However, given the two completely differing cultures and histories of the TB and the HIV/AIDS communities, the Stop TB Partnership needs to develop a fuller understanding of the strengths and weaknesses of these groups.

**Broadening partnerships**

The Stop TB Partnership has well-established technical partners, with a long history of commitment to TB control. These have strong international as well as country-level presence, and include WHO, the Royal Netherlands Tuberculosis Association (KNCV), the International Union Against Tuberculosis and Lung Disease (IUATLD) and the Centre for Disease Control and Prevention (CDC), to name a few. Financial and donor agencies, including the UK Department for International Development (DFID), the US Agency for International Development (USAID), the Canadian International Development Agency (CIDA), GFATM and the World Bank, among others, have worked with and supported the Partnership since its inception.
Linkages with established organisations and agencies specialising in strategic advocacy and communication planning, management and implementation – such as Panos, the Communication for Social Change Consortium, Johns Hopkins University/Center for Communication Programs (JHU/CCP), the Academy for Educational Development, Soul City, and the BBC World Service Trust, to name a few – have been established only very recently. There is an urgent need for the Stop TB Partnership to establish, expand and strengthen linkages with in-country communication specialists and agencies from the high-burden countries. Organisations such as the Southern African Development Community (SADC) Centre for Communication for Development (South Africa), Health Action Information Network (Philippines), the People's Health Movement (Asia), Kara Counselling and Training Trust (Zambia) and Treatment Action Campaign (South Africa), among others, have much to offer by way of contextual experience and communication leadership.

The Stop TB Partnership Secretariat in Geneva has also encouraged a large number of non-governmental organisations (NGOs) and other groups to join the Partnership at the global level. A quick review of the partners' directory shows that, aside from the established technical, academic and governmental partners, there is a multitude of small and medium-sized NGOs and groups linked to the Stop TB Partnership. Aside from a few organisations and some emerging links with PLWHA networks, there are very few large-scale and network NGOs associated with the Partnership. This needs to be redressed. Tremendous momentum has developed in the recent past around the MDGs and fighting poverty, with the mobilisation of large-scale networks of national and international NGOs and civil society organizations (CSOs), such as the Make Poverty History campaign and the Millennium campaign. These have been led and driven by NGOs and CSOs with significant advocacy and mobilising capacities, as well as strong country-level presence. Many large coalitions of in-country organisations, including NGOs, trade unions and community-based organisations (CBOs) that are engaged both in national and regional interventions, are potential partners for wide-scale grassroots mobilisation in the high-burden countries.

The Stop TB Partnership needs to make concerted efforts to engage and link with such NGOs, campaigns and movements, and draw from their experience and expertise so as to mobilise society around the issue of TB and poverty. This may not be easy, as these established and independent players will be less respectful of traditional medical hierarchies of knowledge and status. Constructive criticism and creative tension are to be expected, and should be welcomed.

Facilitating the formation of country-level national Stop TB partnerships has been seized upon by the Stop TB Partnership Secretariat as a means to promote greater involvement of NGOs, CSOs and other stakeholders in the issue of TB. To date, national partnerships have been ‘launched’ in Uganda, Mexico, Pakistan, Indonesia and Brazil. Furthermore, regional Stop TB Partnerships have been mooted for the African, South East Asian and Western Pacific regions of WHO.

While national partnership-building efforts have been noteworthy, it is still too early to draw any useful insights or conclusions, largely because role definition for the national Stop TB partnerships is still evolving. This is further complicated by the fact that nearly all the HBCs have either CCMs (Country Coordinating Mechanisms of the GFATM process) and/or Inter-Agency Coordination Committees. These are expressly constituted to facilitate co-ordination among various partners, which in many instances has led to confusion about the perceived role of a national Stop TB Partnership.
A growing number of NGO partners are involved with national TB programmes in delivering TB services or conducting local communication efforts. However, given that the national Stop TB Partnerships are expected to be led by the national TB programme managers, many NGOs/CSOs, especially those involved in activism and rights-based advocacy, could perceive these national partnerships as simply a means to extend service outreach, rather than a genuine forum for debate, action and holding governments to account. The Stop TB Partnership needs to urgently review its national partnerships development process and ensure that NGOs and civil society groups, especially those specialising in grassroots-level advocacy and activism, can be mobilised around the TB issue.

Models for society review panels or other groupings could be explored at the national level, premised on the centrality of independent and constructive engagement with national TB strategies. These panels should have sufficient autonomy from national TB programmes to feedback critically on plans and performance where necessary. Affected communities and local and international NGOs should all have representation. The knowledge, networks and power to mobilise that these groups bring could represent a real driver for change.

**Working with the non-state sector**

Beyond those partnerships with civil society and other organisations, a significant new challenge relates to embracing the private health sector, referred to here as ‘non-state’. The scope of Public-Private Mix for DOTS treatment (PPM-DOTS), as defined by WHO, implies inclusion of all public, voluntary, corporate and private healthcare providers not yet involved in DOTS implementation.\(^15\) It is now well documented that in a multiplicity of settings and countries, and for a variety of reasons, patients (particularly the poor and marginalised) seek diagnosis and treatment for illnesses from sectors other than the (public) national TB programmes. Furthermore, in a large number of HBCs, the private sector (both ‘for-profit’ and ‘not-for-profit’ health service providers) has a large and widespread presence and reach (e.g. there are an estimated 8 million private health service providers in India), and is in most instances geographically as well as culturally closer to the community than the state-run services. These providers have so far remained largely unlinked to national TB programmes and the DOTS strategy for controlling TB.

The large numbers of private health service providers represent a key constituency for health communicators. They need to be reached with medical guidelines and clear rationales for co-operation within an effective national model for service delivery. Over and above practical support, tools and materials will be needed that show them how and why they should get involved, and that provide incentives in terms of accreditation, strengthened networks, and influence within local structures of power and authority.

Methods for exchanging information with other private health service providers and connecting with national TB programmes are required that are attractive to users, tailored to different contexts, and complementary to other national information and data collection efforts. These must be rigorously tested.

New approaches to fostering public-private partnerships are already underway. However, most technical and policy guidance from WHO on TB control has been primarily aimed at national TB programmes. A new approach, presenting ‘international standards’ for TB care, is now being finalised. This is intended to be a tool for leveraging a better, universal standard/quality of care for TB patients from all health practitioners and providers, whether in the public or private sector.\(^16\)

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These international standards have other implications for health communicators. A supportive companion document, on the rights and responsibilities of patients, is also being prepared by a network of TB patient-activist groups. The core principle underlying these standards is a call to every TB care-provider to treat all TB patients (individually or otherwise) from a public health standpoint – thereby advancing the idea that every TB care-provider is not just responsible for an individual patient’s treatment, but is also assuming responsibility for the community. The international standards of care are expected to form the backbone of the Second Global Plan, and will need strong advocacy and media support for wide-scale uptake and implementation.

### Strengthening health systems

Few other policy areas have generated as much discussion, with so limited results, as that of strengthening health systems. Affordable and effective drugs and interventions exist to reduce much of the burden of infectious diseases. More and more funding is being made available for a variety of interventions. But weak health systems remain a critical constraint to delivering them to the people who need them most. While greater resources are indeed needed to improve health systems in many countries, more importantly, a clearer road map for strengthening health systems – with objectives, benchmarks and a systematic agenda for action – needs to emerge. Superficial, quick-fix and piecemeal approaches may do more harm than good. Vertical programme thinking still pervades the setting of policy agendas, even as the MDG agenda is calling for greater collaboration and a more multi-sectoral approach to health delivery.

The progress and success of TB as well as HIV/AIDS control programmes are almost totally dependent on strong health delivery systems. To achieve the MDGs, especially in Africa, media and advocacy efforts need to keep this topic on the political and public agenda. This will not be easy, as it involves macroeconomic and structural issues. Public attention on the capacity of their hospitals and clinical services tends to peak in times of crisis. Long-term trends, and the relationship of health service capacity to taxation, economic management and market performance, are less appealing. The arguments around vertical approaches and broader health system support need to be articulated in an accessible way for the media and civil society. Interest around the current HIV/AIDS treatment scale-up serves as a vehicle for linking the provision of antiretrovirals with the broader state of public health infrastructure. These linkages should be highlighted in terms of their implications for TB. Part of this communication approach will involve creating the right conditions for a more integrated response within countries.

In Africa, where such interventions are most needed, a combination of systemic factors, including inadequate health infrastructure, poor diagnostic services and a severe health workforce crisis, have hampered the integration of TB and HIV/AIDS services. Exceptional efforts are needed. Rapidly building linkages and advocating with AIDS activists and PLWHA networks about the need for strengthening TB-HIV/AIDS collaborative interventions are of critical importance.

In the face of crumbling health infrastructures in Africa, community-based approaches to TB-HIV/AIDS treatment and care are emerging as one of the most important options. However, the media, the HIV/AIDS activist networks, and the NGO community have yet to fully embrace TB into the HIV/AIDS agenda. While some strong commitments have been made in high-level fora, including statements by Nelson Mandela at the 2004 Bangkok AIDS Conference, follow-through at the community level is urgently needed.
**Maintaining commitments**

Previous advocacy successes mean the fight against TB is at risk of losing momentum even though infection rates are still high. In many countries, a number of basic performance targets on TB are soon to be met. Maintaining commitment in these countries, and among the international community, is therefore likely to be increasingly challenging. For the past five years, expanding DOTS services, to achieve 100 per cent geographical coverage, has been the driving force behind TB control activities. By the end of 2005, large parts of the world, including many of the high-burden regions and countries, are expected to achieve full DOTS coverage. Further, by the end of 2005 or soon thereafter, a significant number of countries also expect to achieve the 70 per cent detection and 85 per cent cure-rate targets. From that critical moment onwards, national TB programmes will move from an active expansion phase to the more difficult task of having to maintain these levels of achievement over many decades in order to bring about a significant decline in incidence, prevalence and death. Once DOTS coverage, case-detection and cure targets have been met, there is a very real danger of losing momentum and of complacency setting in among national TB programmes. The role of the media and of civil society in actively maintaining public pressure and ensuring accountability will, therefore, be critical.

**The need for targets**

Beyond 2005 and its associated targets, the current target means that the date of reckoning will come only in 2015 – a full ten years later, when countries will be looking at whether they have achieved the MDG targets or not. Given the long period between the two ‘target’ years of 2005 and 2015, a demand must be made for fixing intermediate measures of progress. DOTS coverage and rates of TB incidence, prevalence and death are relevant for discussions among the medical and other professionals, but they can become a shield from public accountability. For civil society and the media to monitor progress in TB control, and hold governments to account, more easily accessible targets must be set.
The Second Global Plan to Stop TB – getting communication on the agenda

The Second Global Plan to Stop TB (2006-2015) is expected to be launched by the Stop TB Partnership in January 2006 at Davos, in conjunction with the annual meeting of the World Economic Forum. The Stop TB Partnership is leading the planning process. Building and expanding on the previous Global Plan to Stop TB (2000-2005), the Second Global Plan has been harmonised with the indicators and timelines set out in the MDGs. The Plan is expected to be a road map for TB control over the decade 2006-2015, on the way towards the Partnership’s larger goal to eliminate TB as a global public health problem by 2050. The Second Plan will be a synthesis of seven strategic plans, developed by the seven Working Groups (including the newly formed Advocacy, Communication and Social Mobilisation Working Group) that constitute the core planning and policy constituency of the Stop TB Partnership.

Priority areas for action

Priority communication areas for action to improve the response to TB include:

- **Establishing fora to enable meaningful stakeholder engagement:** Exploring models for involvement in national TB responses, which include affected communities and local and international NGOs.

- **Creative use of media:** Exploring a range of approaches for more creative use of the media, and information and communication technologies.

- **Monitoring the effectiveness of communication:** There is a need to broaden the range of monitoring and evaluation methods, beyond just awareness raising, to include measuring the impact of advocacy, social mobilisation and communication interventions.

- **Linking communication on TB to epidemiology:** There is relatively strong information about the spread of TB in different countries. Communication strategies need to relate to this information, for example, by prioritising risk areas.

- **Increasing communications capacity:** Existing communications staff can benefit from training, and more staff could be recruited to offer communications advice to national TB responses.

- **Collating and simplifying TB communication tools:** An accessible and practical toolkit should be developed offering comprehensive communications guidance to national TB responses.
In the technical, operational and financial domains, the TB community is strongly co-ordinated. There is international agreement around one globally accepted technical strategy (DOTS), one monitoring and evaluation system, and one co-ordinated financial and budgetary plan (the Global Plan) – the ‘three ones’ of TB control, as it were. This is a strong foundation upon which to build the advocacy and communication constituency for the next ten years.

In terms of communication thinking, however, the TB establishment is way behind. While the overt focus on medical aspects of TB and the DOTS strategy has led to the development of robust surveillance, monitoring and drugs delivery systems, it has come at a cost. The lack of attention and importance given to communication generally, especially advocacy and social mobilisation directed at enhancing greater public awareness and ownership around TB as an issue, has resulted in weak participation and engagement by civil society. Work on TB communication, including the role of the media, needs to cut across a number of fields. New frameworks for accommodating all these areas need to be developed. The time is right to bring these perspectives together into one coherent plan.

The health communication field is well placed to benefit the TB response. Planning is already underway and creative new constellations of partners, poised to intervene in the problem of TB, are waiting to play a part. That they should do so in a co-ordinated and complementary manner has immense importance for the response to TB and for the individuals and communities affected by the disease.
For all documents related to the seven Working Groups of the Stop TB Partnership, please see: www.stoptb.org/wg/

For all documents related to the Stop TB Advocacy and Communication Working Group, please see: www.stoptb.org/wg/advocacy_communication/sgcountrycommunication.asp

For all documents of the Stop TB Department of WHO, please see: www.who.int/tb/en/

For a draft version (as of August 3, 2005) of the Strategic Communication component of the Second Global Plan, please see: www.stoptb.org/wg/advocacy_communication/assets/documents/Country%20level%20ACS%20strategic%20plan%20draft%202.pdf

